

Clinical Bioethics Practical Case Study



Pilar Pinto, María Tormo y Benjamín Herreros

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GRATITUDE

T

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Books may have many aspirations but I will only refer to, among the many publications, the ones that delve into human emotions and the ones that illustrate new possibilities and learning. This book, to my knowledge, achieves both because it is a book intended to present the practical implementation of bioethics, for which purpose it uses cases and assumptions that may arise and that have actually occurred in the course of medical practice. It therefore has a clear educational, informative and service vocation and it uses a methodology that facilitates its reading and includes guidelines for the necessary reflection on these issues. In addition, as it captures what happens daily in healthcare centres, it also displays the array of values, beliefs, knowledge and technical implementations that can come into conflict and the difficult task faced by the various healthcare professions. The book deals with patients' rights, their values and their life circumstances as well as with those of doctors and healthcare professionals in general.

How was this book born? I must look back to the year 2008 when ASISA and the Lavinia cooperative that I have the honour of presiding created a Committee for Bioethics and Healthcare Law to grant bioethics consulting and training services to all the doctors in their medical teams, to the members of the Lavinia cooperative and to the professionals who work in the HLA hospital network.

Since that year and over the course of more than 14 years, we have identified the bioethical problems that arise most commonly in medical practice and which our colleagues attempt to solve. During this period of time there have been important regulatory changes related to bioethics – such as the Law that recognises the right of patients to decide to terminate their life- as well as social changes, hugely relevant technological, diagnostic and therapeutic advances and... we have had to face the most important pandemic of the last 100 years. In essence, as in any other discipline, bioethics changes because healthcare and social reality change, as does the implementing legislation. There is no other way of conducting bioethical advice than to study it in the applicable regulatory framework. While this is what has happened to date, everything suggests that bioethical deliberations will be increasingly necessary due to the enormous and even nowadays unimaginable possibilities that science will offer.

At a more recent date, in the year 2019, the above-mentioned Committee, as a practice of their educational and informative task, started to disseminate practical cases in bioethics to more than 11,000 Spanish physicians. This endeavour is

summarised in this book and has resonated in the International Chair in Bioethics and the World Medical Association (WMA). Our sincere thanks to everyone for the reception granted to this project, which now seeks to transcend and become a reference and educational book.

Dear Reader, you have in your hands a book that intends to be useful to you, which seeks to raise awareness about ethical discussion and which shows the need of training in bioethics for healthcare professionals. The use of practical cases is an enjoyable and clear methodology, at the same time not lacking the necessary rigour.

I would like to end this prologue by thanking the authors of the book for their work and wishing that all its readers, dear colleagues, enjoy reading it.

Dr. FRANCISCO IVORRA MIRALLES
President of ASISA group / Lavinia Cooperative

PROLOGUE PROFESSOR CARMÍ

It gives me great pleasure to congratulate the distinguished authors for the formation of this important source of knowledge and guidance. A special blessing and appreciation must be given to Dr. Maria Tormo, Head of the “Book of the Month” Department of the International Chair in Bioethics (ICB). The ICB advances ethics education in a lot of academic institutions across the five continents. The Chair was established over twenty years ago, and its main purpose was to create and promote a revolution in the methodology of ethics education.

The aim was to form a new, modern curriculum of medical ethics to be taught at medical schools all over the world. The need for a modernized curriculum derived not only from the fact that many of the existent curricula were antiquated and completely out of tune with the intricacies of recent scientific developments, but also from the safeguards which are required in the form of educational innovations which will inseminate ethical values into the students, in spite of the present materialistic age in which we live

The goal of the project was to ameliorate the current tuition of ethics in medical schools and to intervene in several plains: To solicit conceptual changes in medical faculties, to form modern curriculum for education of ethics, to train the potential teachers for the instruction of ethics, and to create modern educational tools. materials. The project was expected to introduce students to various non-medical facets of medicine: sociology, economics, psychology and public administration. The idea was to create training programs for teachers and instructors of ethics in medical schools, and to develop novel, modern and sophisticated educational tools and materials in order to facilitate attractive teaching

The new method consisted of a few basic components. First of all, waiver or abandonment of long speeches as teaching tools for ethics education. Second, the initiation of and call for active involvement of the students in the discussion and decision-making process. Third, the use of real medical cases while dealing with ethical dilemmas. Fourth, the collection of such cases from different countries and a variety of cultures in order to formulate a universal method of teaching to fit any site. Fifth, the construction of a uniform structure of the syllabus: Starting with a short review of the case, that is followed by a leading question such as: “What or how should the doctor react in this case? In the next stage the syllabus presents the students with a few alternative ethical options. Finally, after the classroom’s discussion, the teacher may provide the students with a condensed ethical definition or explanation. While as a teaching tool the use of cases may have its detractors, they

are commonly used to convey in a few paragraphs the central elements of a case and to demonstrate in practice the application of concepts.

The cases should mask as much as possible any identifying elements in each case, in order to protect the patients' rights of confidentiality and privacy. Some cases may describe behaviors that are blatantly unethical and even border on legal wrongdoing. They should be kept as an indication that, at times, the dividing line between unethical behavior and criminal lawbreaking is blurred, and that unethical behavior may carry legal consequences when that line trespassed. Following the presentation of each case a binary approach may be used to indicate the possibilities of at least two opposite answers to the problem. Of course, students are invited to develop their own favored ethical choices for the resolutions of these case studies. While this approach may be considered too simplistic, the idea is to provide students with alternatives in thinking ethically, without encumbering them with deep ethical concepts for which texts and other books have been specifically written. The cases should be drawn from real-life experiences. They should be based on simple fact situations, so that the students can address their ethics elements, rather than evade ethical engagements by resorting to technical means or development of additional facts. The use of case studies for medical ethics teaching stimulates ethical debates by calling for a combination of concrete problem solving and abstract principled reasoning. Through case studies, students may learn, firstly, to develop sensitivity for ethical problems and to describe an ethical conflict; secondly, to identify and analyze the underlying ethical principles and values which are relevant to the case, and, thirdly, to stimulate ethical decision-making in the practice of health-care. The aim is to produce a tool and a platform for active participation of students in the decision-making process. Students should learn how to develop a position on an ethical problem and how to justify it. Combined efforts of teaching, educating and training by the use of such a methodology may plant and root in the minds of the students ethical values that should guide every physician providing health-care. The danger of using vignettes would be to become too specific and to concentrate too closely to the issues of the case while forgetting the major socio-political and other relevant implications underlying the cases.

The present book, as well as similar ones should be considered as just a "primer" in ethics with no pretences to be a scholarly text. The editors do not profess to solve all the ethical issues, but rather to inspire the readers to think about all of them more closely and more carefully.

I believe that the current book will be a valuable contribution for the teaching of students and for the professional conduct of doctors in their daily practice, and I hope that the distinguished authors will undertake to compose more similar cases and books.

PROF. AMNON CARMİ, HEAD
International Chair in Bioethics (ICB)

INTRODUCTION

The book *Clinical Bioethics Practical Case Study* lays out real problems faced by health professionals so that the reader may analyse them and decide the best way to solve them. The book's aim is two-fold. On the one hand, it is intended to help professionals learn to reflect and deliberate about the problems they face in their daily job. On the other hand, the book also has an educational goal, as the cases posed in the book can be used for teaching clinical bioethics.

Clinical bioethics is a field that deals with decision making considering the general context in which real life problems happen. Those who are to decide or assess the decision-making process (ethical committees, consultants) must consider the ethical aspects of the problem and, at the same time, regard the clinical questions and the social and cultural background as they cannot be separated, and certainly, the other normative scopes affecting the decision making: deontology and law. This does not imply that the ethical analysis cannot be made independently from the context or the current laws, but that when making a decision we cannot detach it from practical reality.

This approach brings us to the pragmatism of William James and to reflective balance. For James, pragmatism “turns away from abstraction and insufficiency, from verbal solutions, from bad *a priori* reasons, from fixed principles, closed systems and pretended absolutes and origins. It turns towards concreteness and adequacy, towards facts, towards action” (*Pragmatism*, 1907). James proposed two principles to be able to defend an argument: the principle of coherence (avoiding contradictions) and the principle of adequacy. The adequacy or correspondence with reality consists of adjusting to the rest of valuable ideas for life. For instance, a decision in bioethics will be adequate if it has positive effects (pragmatism does not renounce utilitarianism) and if it has a satisfactory relationship with the rest of the life experience: context of the problem, clinical and normative aspects, etc. Here is where reflexive balance arises, which seeks to balance all the factors that appear within a problem: factual aspects, ethical theories, concerns and points of view, specific needs, norms or public priorities. A coherent and justifiable balance should be found among all the factors involved in a problem. When this is achieved, each component of the problem can reinforce and be reinforced by the rest of factors involved.

When analysing the cases proposed, the ethical analysis intends to be coherent with the reality of the existing problem and that the decision be equilibrated

with the rest of the factors at stake. If not, we could be giving a "perfect solution" to the problem which would be lacking a sense of responsibility with the rest of the concrete life experience regarding the problem and therefore, it would be a solution doomed to failure. A further contribution of pragmatism is the provisional nature of solutions. As pointed out by Hilary Putnam, the search for "the solution" is replaced by the search for "a solution we can live with and that is helpful to solve the problem we have at present". The solutions (decisions or advice) we give to the problems posed may be questioned and revised periodically. Furthermore, this must be done.

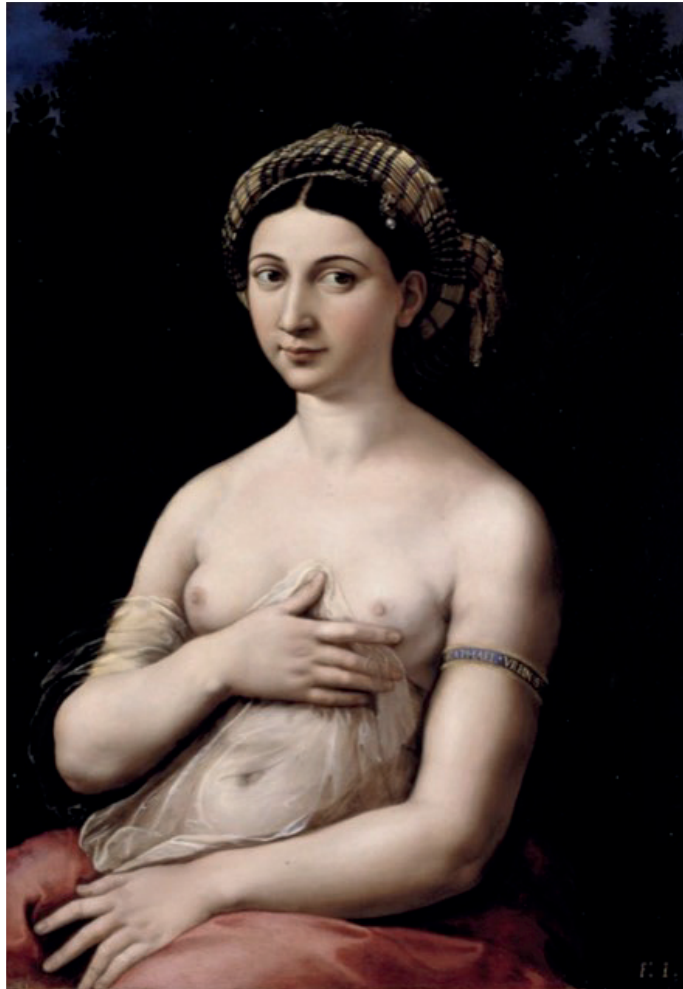
Since the birth of clinical bioethics in the 1960s, many guides have been elaborated to provide assistance in the decision-making process. More or less successfully, these guides attempt to incorporate the key moments of ethical analysis. Some start with the ethical question (for example, J. Fins and F. Miller, or Nijmegen University), while others start from factual/clinical aspects (for example E. Pellegrino, or D. Gracia). The ethical analysis can have an axiological approach (as in D. Thomasna or D. Gracia) or rather a more principlist one (for example Nijmegen University's or G. M. Stirrat's work). In ethical analysis, it is important to distinguish ethical questions from others which are not. As indicated by J. Fins and F. Miller, an "ethical differential diagnosis" should be performed. Subsequently, the discussion and the identification of the possible courses of action and alternatives are carried out in order to choose the best option, which should be the one offering the best consequences and which, in addition, is in equilibrium with the rest of the factors implicated in the problem. The last step is the concrete implementation of the decision. The process includes establishing a plausible action plan, feasible and modifiable accordingly to the evolution of the problem, carrying out a follow up and evaluating (and learning) after applying such action plan (as in Nijmegen University or J. Fins y F. Miller).

Performing all these steps in detail is extensive. For this reason, so that the reader can see more cases, we have synthesized the main moments of the ethical analysis in the following way: **Clinical case:** the most relevant clinical and contextual aspects (social or cultural aspects) are presented, formulating the main ethical doubt at the end of the section. **Ethical analysis:** the main ethical conflict and other important ethical issues are exposed. In certain occasions the "ethical differential diagnosis" is carried out, in other words, other (not ethical) important problems are pointed out. **Possible courses of action:** possible alternatives and ways of responding to the problem are presented. In this moment of the ethical analysis, creativity is crucial, therefore the reader will most probably come up with better alternatives. **Recommended courses of action:** After the deliberation process, the best option to solve the problem is chosen, and the reasons for the choice are explained. **Discussion:** Finally, some of the relevant aspects of the case

under study are commented, sometimes formulated as a conclusion. After analysing each case, we have added a section (“For reflection”) including a film that can be of use to reflect on the case posed, which can also be used by teachers in the classroom.

The chosen method has its limitations, as does any method. The ethical differential diagnosis is not carried out in detail, the procedure does not include an implementation of an action plan or a follow up of the cases, etc. In spite of this, we have faith that the stated cases serve the reader to initiate the ethical analysis of problems that are a part of everyday healthcare assistance.

BENJAMÍN HERREROS



Raphael, Portrait of a Young Woman (*La Fornarina*)
Shows the importance of self-examination in a mixture
of shyness and reality.

CASES REGARDING CLINICAL RELATIONSHIP

The clinical relationship is the basis of healthcare. A good clinical relationship allows the doctor to establish a bond of trust with the patient, which favours mutual communication and treatment adherence. Therefore, when the doctor-patient relationship is appropriate, it becomes a “therapeutic relationship”. However, the clinical relationship is also the origin of many ethical conflicts. The topics of the six cases about clinical relationship selected for the compilation are explained below.

- In clinical relationship, it is important to determine if the patient can decide for themselves, because occasionally it can be difficult to know if they are competent to make decisions. For this reason a case regarding competence assessment has been included to help identify in which cases it should be evaluated. In addition, some guidelines on how to carry it out are provided.
- Information is one of the foundations of the clinical relationship and also a source of conflicts: What does the patient already know? Do they want to be informed? Are they understanding the information? Who else can receive the information? A situation in which some of these issues are considered has been chosen as a second case, aiming to answer some of these questions. The holder of the information is identified while some steps to manage such information are suggested.
- One of the challenges of the clinical relationship is telemedicine and remote management of information. Even more so when it is difficult to confirm the identity of the patient or the spokesperson. For this reason, the third case is about a telephone consultation and about the remote management of information, to explain how to keep ethical and legal guarantees and the quality of the healthcare service within telemedicine.
- The patients who are not competent to make medical decisions are vulnerable, so a special attention in the clinical relationship with them is therefore necessary to identify who their spokesperson is and who is responsible for the decision-making regarding their health. We must make sure, from a healthcare point of view, that the decisions that are made are the most favourable ones for the patient. For the fourth case, a conflictive situation is set out in which the persons responsible for a non-competent patient are identified, with the goal of seeking the most beneficial option for such patient.

- Next, a case of decision-making regarding minors whose parents are divorced is presented. When granting consent for a medical action with an underage patient, in the case that the parents have different opinions regarding health-care actions, the medical team will have doubts about what to do. A series of recommendations are proposed aiming to seek the best interest for the minor and an adequate management of decision making in these cases.
- In the sixth case, the decision-making in cases of underage patients who are over 16 years old is addressed, when these decisions may pose a serious risk for the patient's health. Despite the fact that the legal age for healthcare decision-making and granting consent is 16 years old, when the decision implies a threat to life there are special ethical and legal considerations, as 16 and 17 year-old patients may need a surrogate consent. A case is presented in which the conditioning factors of consent in these situations are explored.

Clinical case

A 60-year-old man with no family support and a severe alcoholism problem with more than 30 years of evolution, with a similar family history, arrives at the hospital emergencies. He has been offered multiple times the possibility of detoxification and alcohol cessation therapy, but he has always rejected them. For two years he has been in bed practically all day. He has only accepted two hospital admissions, coinciding with serious respiratory processes (pneumonia). In the last 5 months he has begun to eat increasingly less, this leading to a situation of severe malnutrition. He has been given enteral nutrition preparations, but he refuses to take them. Nevertheless, he takes the medication that is being prescribed. When being asked why he takes the medication and yet does not eat, he answers: “to prolong my agony.” In the present time, his alcohol intake is one bottle of whiskey per day and two liters of beer.

He has been asked what to do in case of deterioration, to which he responds that he does not want to be admitted in hospital. The possibility of requesting a mental health consultation to assess a forced psychiatric admission has been ruled out, given the foreseeable total therapeutic ineffectiveness of this measure. Two days before attending hospital emergencies, he begins with melanic stools and dizziness. In the emergency room, hemoglobin is 7.8 g / dl. He is again asked about the convenience of admission, as well as the risk of remaining at home, bleeding and with low hemoglobin, and reiterates his refusal to being admitted.

How should we act with this patient? Is the patient competent to make medical decisions? And, if so, do we have to respect his decision?

Ethical Analysis

- We are facing a case of rejection of treatment, but there are doubts about the patient's competence to decide, since he is rejecting the most suitable option from the medical point of view. Ethically, we must respect this decision as long as the patient is competent and makes the decision freely and voluntarily.

- Therefore, once we have identified that there are doubts about the patient's competence, our priority will be to make a complete evaluation of the competence to make the specific decision that the patient wants (reject an admission with an acute digestive hemorrhage that can compromise life).

Possible courses of action

- Admit the patient in psychiatry against his will and, once admitted, take the measures that the doctor considers appropriate.
- Confirm if the information we have about the patient is adequate and sufficient to make the decision. If not, expand the information.
- Assess whether the patient is competent to decide on medical discharge and detoxification.
- If the patient is competent, respect the decision of the patient and offer the alternatives that help him not suffer during the process (for example, palliative care at home).
- If the patient is not competent, a decision must be made by proxy.
- Discharge the patient, given that he has refused the prescribed treatment.

Recommended courses of action

- Check whether the patient has been well informed, and that rejection is not due to insufficient or deficient information.
- If it is considered that the patient is incompetent at that moment to refuse admission, if possible, the doctor should try to improve his competence so that he can decide autonomously. For example, if the incompetence were a consequence of the anemia he must be transfused and see if he improves cognitively, or if it is due to a syndrome of alcohol deprivation, that syndrome must be treated.
- If after that the patient continues to be non-competent, we should try to respect his previous indications (previous instructions or other information on what course of action he would have wanted in such a case) and if we do not have such information, we must make a decision by substitution. In these decisions, the closest relatives are those who decide, seeking the best interest

for the patient. If the doctors detect that a post-replacement decision does not seek the best interest for the patient, they must request judicial authorization to act seeking the best interest for the patient.

- If he is deemed competent, as long as there is no risk of harm to third parties (as it is in this case), the decision must be respected: the patient considers what is most beneficial to him according to his preferences and objectives. However, rejection does not have to be total, which means it may be that he rejects admission but not blood transfusion, endoscopy or medical treatment (omeprazole, ferrotherapy, etc.), so that, although he is not admitted, the possibility of a transfusion and treatment with subsequent medical follow-up must be suggested.

Discussion

Facing conflictive decisions, it is crucial to assess competence carefully. In order to evaluate it, the level of understanding of the patient must be verified. This requires answering the following questions:

1. Does he understand the information that he is being given? The doctor must make sure that he understands the nature of the procedure, the risks, alternatives and the consequences of the process.
2. Does he understand his clinical situation and what the consequences are if the procedure is not performed? The competence is assessed for the specific situation of the patient at that time and for the procedure that will be performed, so it is important that he understands what the consequences are for his health and for his prognosis if he does not follow the treatment.
3. Is he able to reason and justify his answers and choices? The patient must be able to justify his decision based on his values, beliefs and life goals.

In addition, the patient must be able to express his decision, not being essential for it to be verbally. If after a thorough and deliberate interview the doctor still has doubts about the competence of the patient, it would be necessary to evaluate the patient with some semi-structured interview. The most recommended model is the Mc-Arthur Competence Assessment Test (M-CAT), due to the abundant experience with it. It is expectable that after this evaluation the professional will know whether the patient is competent to make the decision at this stage. If the doctor still has doubts about the competence of the patient, they could ultimately request an interconsultation to psychiatry, but always as a last resort, since whenever possible, it is the doctor responsible for the patient who must assess the competence.

For reflection:



- FILM: Still Alice.
- DIRECTOR: Richard Glatzer, Wash Westmoreland.
- YEAR: 2014.
- ANALYSIS: In Still Alice (2014), linguist Alice Howland (Julianne Moore) starts suffering from early symptoms of premature Alzheimer. The neurologist that studies her isn't very friendly, but Alice notices that he cares about her and seeks her best interest. When she has to give a lecture about how she is living her illness, Alice invites Dr. Benjamin (Stephen Kunken). They have a very fruitful professional relationship, with reciprocal acknowledgement and trust. However, Alice will gradually lose cognitive capacities, which will condition her life and the decisions she will have to face.

Clinical case

Luis is 58 years old and has a history of hypertension and obesity. He smokes 20 cigarettes a day and moderately consumes alcohol. A year ago he underwent treatment for pancreatic adenocarcinoma at the head of the pancreas, receiving adjuvant chemotherapy. He comes to the emergency room due to fatigue, anorexia and a loss of 10kg. He is assessed by a general surgeon who decides to request some outpatient tests (a tumor marker analysis and a CT scan of the abdomen) and refer him for a consultation as a priority patient. Luis does not show up on the day of the consultation. Instead, his daughter (Ana) comes with the results from the outpatient tests that had been ordered when he was in the emergency room. She mentions to Dr. Garcia that she has read the results of the tests, that the cancer has recurred and that there seems to be liver metastases. Ana does not want her father to know the diagnosis, she explains that her father “has been very sad since the death of her mother 6 months ago”. Dr. Garcia reads the results of the CT performed as an outpatient, which stated the existence of liver metastases and peritoneal carcinomatosis. Dr. Garcia asks himself if and when this situation happens, he should inform the patient or if it is better to handle the case as requested by Ana.

Ethical Analysis

Conspiring and/or a pact of silence is a common situation in healthcare. It consists in not informing the patient about their clinical status at the request of their family and / or relatives. The Conspiracy of Silence poses an ethical and legal conflict that puts the doctor between the patient and their family and can end up, in some cases, complicating the clinical relationship. In the Conspiracy of Silence there is a conflict between the right to information (and, therefore, the right to make decisions) of the patient and the family decision to protect their relative, when they paternalistically consider giving that information to the patient as harmful. However, in trying to protect the family member, they are actually hurting them. An uninformed (or poorly informed) patient doubly suffers during the health process: they not only suffer from the disease but they also suffer from the concealment of such disease and the inability to know and decide.

Possible Courses of Action

- Stop treating Luis due to the conflict with his daughter.
- Respect Ana's decision not to inform Luis, which is to say, continue to monitor him without informing him.
- Tell Ana that what she is asking for is wrong. The information is her father's, not hers.
- Expel Luis's daughter from the consultation and call Luis immediately to inform him of his results.
- Explain to Ana that it is both legally and ethically necessary to inform Luis of his results.
- Negotiate with Ana, given that the process Luis will need to go through will be difficult, the best way to inform him, if necessary between both of them: how, when and where.
- Refer the case to Palliative Care who can help guide Luis and his daughter through the process.
- Make an appointment for Luis to have a consultation as soon as possible. Tell Ana that she may accompany him if Luis wishes.

Recommended courses of action

- Explain to Ana that it is both legally and ethically obligatory to inform Luis. It is important that Dr. Garcia explains to Ana that giving the information is the responsibility of the Doctor to the patient and only if the patient requests it, can he give information to her regarding his clinical situation and care process instead of to him.
- Negotiate with Ana about the best way to inform Luis, if necessary between the two of them, given that the process will be hard. The ideal way to proceed is that Dr. Garcia collaborates with Luis's daughter. He should start by explaining how important it is for Luis to know his clinical status and prognosis so that he can decide his life according to those expectations. In addition, the care process can be complex and require difficult decisions at the end of life, such as limitation of therapeutic efforts and shared care planning.

- Make an appointment with Luis as soon as possible, to give him the results of his tests and to explain his clinical status. Tell Ana that she may accompany him and be at the consultation if Luis wishes. Initially Luis will be asked what it is he already knows, if he wants to be informed and if he wants his daughter or other relatives to be informed. If so, Ana or the people Luis has chosen to accompany him in the information process may be present at the consultation.
- During the first consultation Dr. Garcia should assess Luis's competence in order to determine what his decision-making capacity is.
- Additionally, Luis can be offered the possibility of a referral to a Psychologist to help him manage the news.

Discussion

Conspiring and/or a pact of silence is a common situation in healthcare. It consists in not informing the patient about their clinical status at the request of their family and / or relatives. The Conspiracy of Silence poses an ethical and legal conflict that puts the doctor between the patient and their family and can end up, in some cases, complicating the clinical relationship. In the Conspiracy of Silence there is a conflict between the right to information (and, therefore, the right to make decisions) of the patient and the family decision to protect their relative, when they paternalistically consider giving that information to the patient as harmful. However, in trying to protect the family member, they are actually hurting them. An uninformed (or poorly informed) patient doubly suffers during the health process: they not only suffer from the disease but they also suffer from the concealment of such disease and the inability to know and decide.

The right to receive information is essential for adequate healthcare. The information is necessary so that the patient may be well informed and thus may choose what is best for them during the care process. It is therefore a prerequisite for decision-making and for trust in the clinical relationship. However, the patient has the possibility to choose that the information be communicated to another person instead or that the information is not given to them nor any third parties.

A patient who freely decides to decline receiving the information, must equally consent to the procedures and assume the risk of possible complications, if they wish to be treated, even though they are not informed.

Facing a Conspiracy of Silence, it necessary to:

- Confirm with the patient what they know, what information they want to have, and whether they want to inform family or relatives of their pathology. It is the patient who should decide.
- Explain to the family carefully that the right to healthcare information is an ethical, deontological and legal obligation of any healthcare professional.
- Suggest that other healthcare professionals participate (psychologists, social workers, lawyers) in order to help them through this difficult care process. If necessary, the BioEthics Healthcare Committee can be consulted.
- Never abandon the patient, even if they do not wish to be informed.
- Record the decisions that are made in the patient's medical history.

For reflection:



- FILM: Irreplaceable.
- ORIGINAL TITLE: *Medecin de campagne*.
- DIRECTOR: Thomas Lilti.
- YEAR: 2016.
- ANALYSIS: Every inhabitant of this rural area can count on their doctor Jean. Pierre to examine, auscultate, treat and appease them day and night, 7 days a week. Now Jean-Pierre is ill, he has been diagnosed with cancer and a new doctor joins him to help him treat his rural patients. Natalie, a young doctor, will come from the hospital to collaborate with him and will have to adapt to this new life and replace a doctor who seemed irreplaceable. She will have to learn to treat and speak to the patients in a different way.

Case study

Joaquín, an 84 year old man, has a history of obesity, hypertension and type 2 diabetes. He came into the primary care consultation alone because he has been feeling very tired lately. His primary care physician Dr. Ballesteros, performed a general examination with no findings of interest and ordered some tests. Joaquin is informed that given the current state of the pandemic (April 2020), he will be given his results over the phone. When confirming his telephone number at the administration desk, Joaquín asks that they instead call the telephone number of a caregiver who works for a few hours at his home, because “I can’t figure out how to use the cell phone my daughter bought me”. The clerk changes the contact number, but does not register this key information in the patient’s medical record. The doctor finds the existence of macrocytic anemia. When she calls Joaquín, a woman who identifies herself as Lorena answers the call. Dr. Ballesteros asks to speak with Joaquín and she informs the doctor that she works for him doing housework and also runs his errands and helps with other things he asks her to do as he doesn’t deal with new technology well. Dr. Ballesteros doesn’t know Lorena nor is she aware of the situation, but she supposes that if Joaquín has given this telephone number as a contact, it is because he authorized Lorena to receive information about his health. Lorena also asks the doctor to email her the results of the tests and a report with the information, so that she can forward it to Joaquín’s daughter, who lives abroad. Dr. Ballesteros isn’t sure if she has done the right thing by informing Lorena by phone and if she should send Joaquín’s clinical documentation by email.

Ethical analysis

Telemedicine, in its various forms, is a form of health care that has gradually acquired greater applicability and has become more widely used especially since the onset of the COVID-19 pandemic. For telemedicine to be acceptable from an ethical, deontological and legal standpoint, it must be carried out with certain guarantees. These guarantees are intended to ensure that certain values and patients’ rights are not violated. Firstly, for telemedicine to be acceptable, it should only be used in cases where face-to-face care, due to the particular circumstanc-

es, is not possible. It mustn't be forgotten that, as a general rule, face-to-face care is the standard for medical care, it is the model we use that ensures the highest quality of healthcare.

Though a consultation through telemedicine means can be useful in many situations (results communication, follow-up of certain pathologies, overcoming geographical barriers or, as in the present case, in the midst of a pandemic situation), it must be accepted and consented by the patient. Therefore, telemedicine poses many ethical and legal issues that must be taken into consideration, among others: the quality of the healthcare being provided, consent, the use of technological means themselves, the protection of confidentiality or the access to clinical documentation.

Possible courses of action

- Dr. Ballesteros should not give information to Lorena in person, by telephone or in writing, without Joaquín's explicit consent to do so.
- Ask Lorena to call as soon as she is with Joaquín, in order to give the information directly to him.
- At the end of the consultation, go to Joaquín's home to explain the results to him in order to avoid him going to the health center because he is a high-risk patient.
- Book an in-person appointment with Joaquín to give him the results and explain them to him.
- Refer Joaquín to the patient care services to give him a copy of his test results.
- Explain to Joaquín the current difficulties with face-to-face consultations, present him with the alternatives for remote assistance and decide with him who will be the contact person authorized to receive medical information on his behalf.
- Give the information about the results to Lorena by phone, but inform her that she will have to go to patient care services to request a copy of the report and analysis.
- Given the technological barriers in assisting Joaquín, send Lorena the requested documentation.

Recommended courses of action

- Dr. Ballesteros should not give information to Lorena in person, by telephone or in writing, without Joaquín's explicit consent to do so.
- Given this is not an emergency, but it does provide relevant clinical information, the physician has to arrange an appointment with Joaquín for the telephone consultation. To this end, the health center will have to make arrangements with him and his caregiver.
- Once the scheduled appointment has been made (with Joaquín and his caregiver to assist him), the physician must identify herself, ask for Joaquín and try to talk to him directly. Only if the communication with Joaquín is not effective and if Joaquín explicitly authorizes it, Dr. Ballesteros will be able to give the pertinent explanations to Lorena.
- If Dr. Ballesteros considers it necessary, she will arrange a face-to-face appointment with Joaquín to give him the results and explain them to him. In this face-to-face consultation (or in the first one she has with Joaquín), he must be explained what the teleconsultation is and how it works, especially regarding whether he authorizes someone to assist him in successive teleconsultations.
- However, if the the health context due to the pandemic or other reasons put Joaquin's health at high risk, Dr. Ballesteros will schedule a consultation at Joaquin's home to explain the results.
- With regard to sending the report and the analysis, in order to do so: 1) you must have Joaquín's authorization; 2) the health center must provide a secure means of sending it. If these two requirements are not met, it must be explained to Joaquín that either he or someone with his authorization must go to the health center to pick up the requested information.

Discussion

It is essential that the physician obtains the patient's consent for a remote consultation in substitution for an in-person one.. One of the main barriers to telemedicine is the technology itself, which is not always accessible to every patient. The use of technology (e-mails, telephone) can be a problem for many patients, which in turn further reduces the quality of care provided remotely. It is imperative to be certain about what knowledge the patients have about the technology

used in telemedicine and their ability to access it, as afterwards the medium to be used for communication with the patient should be agreed upon. If patients do not have good access to telemedicine, third party assistance should be considered, provided the patient agrees and consents, as they may need to be present during the exchange of information.

Confidentiality and professional secrecy are essential for a good doctor-patient relationship. However, telemedicine puts data confidentiality at risk because many of the systems used are not really secure. In order to provide appropriate clinical care and preserve the patient's trust, it is vital to ensure the confidentiality of the data transmitted through telemedicine. Only institutional means should be used, avoiding personal emails or telephones that do not guarantee the protection of such information. The patient has the right to access clinical documentation, but this should not be shared through channels that do not guarantee confidentiality. Institutions should enable secure and adequately encrypted means for teleconsultations and documentation transmission. If this is not the case, information should not be sent or transmitted via telemedicine.

Lastly, it is important to remember that the most suitable form of clinical care is face-to-face. However, if due to a contingency (as in the case of Joaquín), clinical care must be performed remotely, normally via a telephone consultation, it should be scheduled so that, for example, the patient who requires help can arrange to have it available at the time of the call. Not forgetting the organization of the healthcare activity itself. Once the telephone consultation has begun, the healthcare professional must identify themselves and, in order to preserve the patient's privacy, they must know who they are talking to before giving confidential information. After that process is completed, the teleconsultation can begin, making sure to be especially careful with the quality of the communication, and confirming that the patient understands the information that is being given. Finally, any remote healthcare action should be considered a medical act and, as such, should be recorded in the patient's medical record.

For reflection:



- FILM: My Life Without Me.
- SPANISH VERSION: Mi vida sin mí.
- DIRECTOR: Isabel Coixet.
- YEAR: 2003.
- ANALYSIS: My Life Without Me portrays young Ann (Sarah Polley), who leads a sad and rutinary life in Vancouver. She makes her living as a cleaner in order to raise her two daughters. When she goes to a medical appointment to take some tests, she finds a dehumanised system. Nobody speaks to her, nor explains or understands her problems. When Dr. Thompson (Julian Richings) tells her she has cancer, she finds herself having to comfort the doctor because he doesn't know how to talk to his patient or confront the situation. Dr. Thompson is not used to dealing and relating with people. Initially, Ann breaks down, but she pulls together quickly thanks to her enormous creativity. The best way of giving information is face to face, but it is necessary to know how to inform.

WHO IS THE DESIGNATED REPRESENTATIVE THE FAMILY OR THE CAREGIVER?

Case study

Manuel, 72 years old, suffers a stroke and is thus admitted to the hospital. He comes to the center accompanied by a woman who identifies herself as his usual caregiver, although she does not provide any documentation to prove it. In order to proceed with the admission process, the hospital administration asks the caregiver for the appropriate documentation to carry out the necessary procedures. Among the documents provided was Manuel's ID card. On the fifth day of admission, some of the patient's nephews ask to speak to the hospital director showing a complaint filed for occupation, regarding the use of Manuel's home by the caregiver and her family while he has been in hospital. Immediately afterwards, the caregiver presents a notarized document to the hospital management showing that Manuel granted her full legal powers. The medical management team consults with the physicians responsible for the patient and they inform them that these powers of attorney were given while the patient was already hospitalized and, in their clinical judgment, the patient was not competent to grant such powers at that time, having signed them with his fingerprint. The next day, the physicians state to the facility director that Manuel may be discharged and that the caregiver has expressed her desire for him to go to his usual home under her care. However, the nephews inform the director that they are looking for an assisted living facility for their uncle and that they do not believe the caregiver should make that decision. Additionally, the physicians have doubts about the care he will be able to receive at home. In view of this situation, the hospital management decides to consult its ethics committee to clarify who the patient's designated representative and valid interlocutor is, since Manuel has been declared by medical opinion to not be of sound mind to decide. Should the patient be taken care of by the caregiver through the power of attorney or by his nephews and nieces, who are his closest relatives?

Ethical analysis

The priority in this case must be the protection of a vulnerable patient and the pursuit of his well-being and safety, whether by family members or his caregiver. In any case, the primary issue is to seek what is in the best interest for Manuel. Limitations in decision making should be recorded in his clinical history. Firstly, it is essential to respect Manuel's wishes and for this reason it is necessary to: assess his compe-

tence, determine whether his incompetency is permanent or transitory (prognosis), whether he has registered prior instructions and whether he had expressed his preferences to professionals. If he is found not competent, it will be necessary to identify the most appropriate proxy. It is important to keep in mind that when making decisions by proxy, the best interest of the patient should be sought.

Possible courses of action

- Conduct an assessment of the patient's competence and, if possible, explore his preferences.
- If feasible, estimate whether the patient can regain his competence and in what time frame.
- Identify whether there are any prior instructions or any indication in the medical records Manuel's preferences.
- Inform the caregiver because she has the legal powers to represent Manuel and make decisions on his behalf. If requested, discharge him to his home under the care of the caregiver.
- Inform the family, in the understanding that the powers of attorney are not valid. He will be discharged for transfer to an assisted living facility.
- Subsequent follow-up to see how the patient is evolving and assess whether additional legal measures are necessary.
- Refer the case to the competent court and not make a decision regarding the hospital discharge until the court's decision is known.
- Not give information to the caregiver or family members, either by telephone or in writing, until it is clear to whom the information should be given.
- Consult with the Social Worker.

Recommended courses of action

- The physicians and hospital management shall act at all times in the best interest of the patient. This principle will guide their decisions.
- Perform an assessment of the patient's competence and, if possible, explore the patient's preferences. Identify whether there are any prior instructions or any indication of preferences in Manuel's medical record.
- If feasible, estimate whether the patient can regain competence and in what time frame.

- Refer the case to the appropriate court and not make any decision regarding the patient's hospital discharge until the court's decision is known.
- Not give information to either the caregiver or family members, either by telephone or in writing, until it is confirmed to whom the information is to be given.
- Wait for the judicial body's decision before discharging Manuel. Extend his admission keeping him in hospital until the best destination for his discharge is determined.
- Bring the case to the attention of the social services to explore all available resources and carry out a follow up with the patient after discharge. Maintain coordination with social services at all times.
- Record all actions in the patient's medical record.

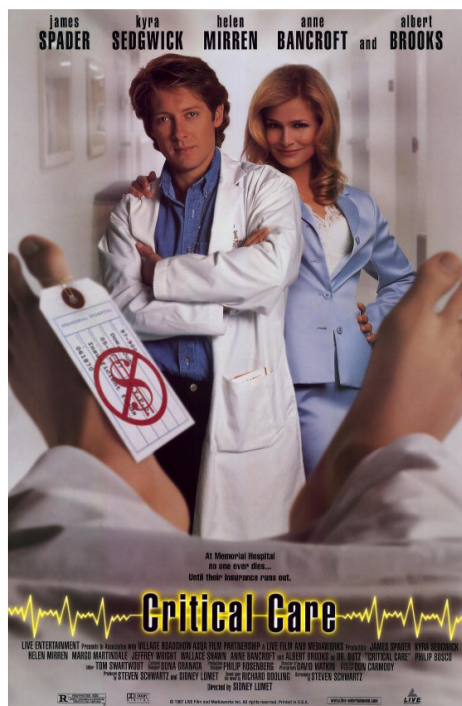
Discussion

Although it is preferable to avoid the judicialisation of medical care, if the doctors conclude that Manuel was not in a position to grant power of attorney on the date he did, then in this case it would be advisable to bring the facts to the attention of the Court of Guard in order to assess who the legitimate representative of Manuel is, especially if there are doubts as to whether the caregiver is capable of providing Manuel with the care he needs. The Court should be consulted as to whether the power of attorney is valid and, based on this, decide who should be Manuel's representative. Pending a judicial decision (transfer to the home with the caregiver or to a nursing home, following the wishes of his nephews and nieces), in order to protect Manuel's well-being, his hospital admission should be maintained. It should be noted that if the doctors consider that Manuel was competent to sign the notarized document (meaning he was aware of what he was signing), the legal representative would be the caregiver.

Regarding the other legal aspects (occupation of the home, alleged improper procurement of powers of attorney), these are problems that are beyond the competence of the clinicians and the management of the medical facility because legal action is already in process. Otherwise, if physicians (or any other professional) suspect or detect a possible crime, they have an obligation to report it. This is not a special duty of healthcare professionals, but a general duty as citizens.

Whatever the final discharge destination is, it is recommended that the medical team coordinate with social services to explore all available resources and keep a follow up with the patient after discharge. This should be done for clinical reasons as well as from a social perspective.

For reflection:



- FILM: Critical Care.
- DIRECTOR: Sidney Lumet.
- YEAR:1997.
- ANALYSIS: Young Dr. Werner Ernst (James Spader) is a second year resident in the Intensive Care Unit. He has a patient admitted in critical condition. His two stepdaughters Felicia Potter (Kyra Sedgwick) and Connie Potter (Margo Martindale) have different opinions on what decision to make, whether keeping him alive or disconnecting him from life-support. The background of the family dispute is a juicy inheritance of 10 million dollars, apart from the additional monthly cost of 112,000 dollars for keeping their stepfather connected to the respirator. Felicia will try to seduce Dr. Ernst to achieve her goal, which is to disconnect the stepfather as soon as possible. However, Connie, who has strong religious beliefs, wants to prolongue his life as long as possible. Meanwhile, his supervisor insists to Dr. Ernst in providing treatment only to those patients with an adequate healthcare insurance. The young doctor finds himself in a difficult position, having to make sure he follows the best interest of his patient unable to decide, amidst the family conflict and a complex system.

Clinical case

Pedro is 7 years old. His parents have been told at school that he is a very “lively” child, and the teachers regularly complain about his behaviour. After a mental health assessment by a psychologist and a psychiatrist, Pedro is diagnosed with attention deficit hyperactivity disorder (ADHD). Following a careful evaluation, they recommend two alternative therapeutic options: psychotherapy sessions, or, psychotherapy sessions in addition to pharmacological treatment. Pedro’s parents are divorced and the court has established shared joint custody. Pedro’s mother prefers to start the pharmacological treatment together with the psychotherapy as she feels psychotherapy on its own will not suffice. However, the father prefers to delay the start of pharmacological treatment as he is concerned about the possible side effects of the drug. He wants to give the psychotherapy sessions a chance, and only if those sessions are unsuccessful, would he agree to pharmacological treatment at a second stage. The mental health team is unsure in this case of who should make the decision regarding Pedro’s treatment since the parents are divorced but share equal joint custody. Who should make the decision regarding Pedro’s treatment?

Ethical analysis

The patient is a minor and thus requires consent by proxy. Wherever possible, the minor should be informed about their situation and the process, adapting the information as needed so that the child understands. Regardless, the decision must be made by their legal representatives, who in this case, are both the parents. When parents are separated or divorced, surrogate decisions can become complex, particularly when they do not agree on what is best for the child. If, as in this case, both parents have joint legal custody, and therefore also the shared responsibility for decisions regarding the child’s health, then both parents must consent to any medical procedure or treatment. In cases such as these, there is a conflict between the protection of the child’s health and the respect of each parent’s personal autonomy to decide which treatment is best for their child.

In decisions made by proxy, an important ethical nuance must be taken into account: the proxy decision must always seek what is in the best interest of the represented party, in this case, the 7-year-old minor. The decision must be solely focused on what is best for Pedro's health, and what will be of greatest benefit to him, while at the same time ensuring the least possible harm (side effects and risks). In extreme cases, if the proxies make a decision that is clearly detrimental to the health of the minor, the medical team may consider not carrying out the proxies' decision, justifying it on the basis of protecting the minor's health.

Possible courses of action

- Given that the parents cannot come to a mutual agreement, refer the case to another center.
- Instruct Pedro's parents to return to the medical consultation once they have reached an agreement regarding Pedro's treatment.
- Analyze all the different therapeutic options with the care team and assess if any of them would be best for Pedro.
- Begin with psychotherapy, as the father pointed out, and if it is not effective then add the pharmacological treatment.
- Interview the parents individually to confirm that both of them understand all the treatment options, including what the benefits are and any possible complications.
- Attempt to have a joint consultation with both parents in order to deliberate with them on the best possible treatment for Pedro. Give them some time to try to reach an agreement.
- If the parents cannot reach a consensus after the consultation, then tell the parents to inform the appropriate judicial authority so that they may assess what treatment should be prescribed for Pedro according to the opinion of experts.
- Given the discrepancy in opinion between both parents, inform the appropriate judicial authority for immediate action.

Recommended courses of action

- First, discuss the different therapeutic options with the care team and assess what the best option for Pedro is. The care team should do this by carefully re-evaluating the case and looking at the alternative treatments to determine whether any of them might be more beneficial or more harmful.
- Second, whenever possible, try to have a joint consultation with the parents to help them deliberate and try to reach an agreement. If the care team determines that one treatment option is preferable to the other, then this should be explained to the parents so that they understand the reasons as to why this is the best option for Pedro. Allow the parents to take some time to try and reach an agreement.
- If a joint consultation is not possible, hold a separate interview with each parent to confirm that they have received all the information they need to make the decision and that they understand both the benefits and potential complications of each of the options.
- Pedro should be informed throughout the decision-making process. His health issue should be explained to him in an adapted and understandable way so that he may comprehend it to the best of his abilities.
- Lastly, if the parents are unable to reach a consensus after their consultation, then inform them that the appropriate judicial authority should be informed so that the question of what treatment may be the best for Pedro can be assessed according to the opinion of experts. This intervention by the judicial authority should be carried out as a last resort and in Pedro's best interest.

Discussion

- Decision-making about children of separated or divorced parents is often hindered by the parents' relationship. Although it is not the function of the care team to intervene in family dynamics, when a child is being negatively affected due to the discrepancies between their parents, then we must try and help them come to a consensual decision that is in the best interest of the child.
- Keeping the patient's well-being in mind, it is advisable to go through the decision-making process jointly with the parents trying to help them put aside their conflicts and focus on the common goal.

- It might also be necessary to meet with the parents individually, although in these situations it is preferable to have a joint consultation. This is to ensure that both parents receive the same information and that they do not use any information received for their own benefit and/or against the other spouse.
- In extreme cases where the parents are unable to reach an agreement due to their personal conflicts, it may be necessary to request an authorization from the appropriate judicial authority before carrying out the treatment that has been determined to be most beneficial for the child. In any case, this measure should be used as a last resort, among other reasons because it could be detrimental to the minor since it may require a forensic assessment, which may be disproportionate.

For reflection:



- FILM: Lorenzo's Oil.
- DIRECTOR: George Miller.
- YEAR: 1992.
- ANALYSIS: Decisions about children's health are not easy, both whether the parents are divorced or not. The Odone couple (Nick Nolte and Susan Sarandon) confronts the medical community, questioning their scientific methods. They search for an alternative remedy for their son Lorenzo's illness (played by Zack O'Malley Greenburg), the rare and severe adrenoleukodystrophy. Lorenzo's parents, aware that medical research can achieve great advances, want everything that can be done for their child. They come into contact with Dr. Gus Nikolais (Peter Ustinov), an authority in the field of adrenoleukodystrophy. He informs them of a new treatment, a diet which is free of long chain saturated fatty acids. Lorenzo's parents doubt about letting their son participate in the research. In order to make a decision, they ask the doctor about the possible risks and benefits. They want to have the highest guarantees before participating.

Clinical case

Juan is 17 years old. Three years ago, at the age of 14, he was diagnosed with leukemia, treated and the results were satisfactory. However, when 4 months ago he began to feel very tired and lethargic and stopped practicing hobbies in his free time, his parents immediately consulted his hematologist. At the hospital, after suffering a relapse he was re-diagnosed with leukemia and informed of the different therapeutic alternatives. Juan refused all of them: he preferred to continue with a conservative, symptomatic treatment and, if necessary, possible palliative care. He did not want to stop living his normal life, or condition his life around his illness. His parents did not agree. They agreed with the medical team, that he should be treated. Juan did not refuse a psychiatric exam. The psychiatrist concluded that he did not present any pathologies nor was he under any coercion or stress, thus considering him competent to understand his decision and its consequences. The medical team decided to bring the case to the Ethics Committee for Healthcare with the following question: in the case of a competent minor facing a serious illness, whose opinion should take precedence, the parents' or the minor's?

Ethical analysis

We face the case of a 17-year-old patient diagnosed with leukemia refusing treatment. His parents oppose this decision and agree with the medical team that this is not what is in the best interest of their son, and they prefer that he accepts new treatment. It is important that, to begin with, we verify the reasons why Juan is refusing treatment, and if the information he has received and his understanding of that information is adequate. It is entirely possible that initially he feels overwhelmed or burdened by the situation. This is why it would be reasonable to give Juan time to adjust to the news and its consequences.

If this method does not work, it is important to keep in mind that Juan is competent to make decisions (based on a psychiatric review), he is not under any pressure or stress and is fully aware of the consequences of his decision not to receive treatment. The patient is only willing to go through symptomatic treatment and receive hospice care, if and when that moment comes.

Possible courses of action

- Respect the opinion of the patient, which is against that of his parents and doctors: He is 17 years old and was determined by a psychiatrist to be competent of making decisions.
- Ensure that the information given and the understanding by the patient regarding treatment is appropriate: benefits, secondary effects, consequences of not receiving treatment, therapeutic alternatives.
- Give the patient a reasonable amount of time to process the information and to reconsider the treatment options and their consequences.
- Look into why the patient is refusing treatment.
- Follow the opinion of the parents and, in this case, that of the medical team. Decide between them the best treatment option to follow.
- Bring the case before the Juvenile Protection Services in order to protect the health of the minor and be able to make a decision against his will.
- Bring the case before the Juvenile Protection Services in order to decide if the patient can be emancipated so that he may make his own health decisions, since he is 17 years old and was found competent.
- Register the conflict and the respective decisions made in the clinical record.

Recommended courses of action

- The physicians in charge of the case must make sure that both Juan and his parents have all the necessary information in order to make a decision.
- Health Services should do everything possible to make sure that Juan understands the consequences of his decision. Likewise, it is necessary that they find out the reasons why he is refusing treatment despite its consequences. It might be beneficial to give Juan a reasonable amount of time to process the information and think about the various alternatives and their consequences.
- Similarly, the parents should be supported so that they may help their child make the right decision.
- If the parents make a decision in the best interest of Juan's health, then it is not necessary to contact the Juvenile Protection Services at the duty court. Only in the case that Juan is very reluctant and physically refuses the treatment (does not go to check-ups, prevents treatment being performed, etc.)

should the case then be brought to the attention of the Juvenile Protection Services in order to protect his health and treat him against his will.

- Faced with a serious vital risk, physicians should treat the patient in accordance with the decision made by the parents, at least until he turns 18.
- It is recommended to report the case to the hospital management.
- Each step taken must be registered in the medical records.

Discussion

In Spain, in 2022, law 41/2002 regulating the free will of a patient establishes in article 9.3.4 the following: *“When treating emancipated minors or minors of at least 16 years old [...], consent cannot be given for representation. Notwithstanding the provision of the previous paragraph, in the case of a serious risk to the life or health of a minor, according to medical criteria, consent will be given by the legal representative of the minor, once the opinion of such minor is heard and taken into account”*.

The conflict in this case arises because the patient is 17 years old and is facing a serious risk to his health. Given that he is under 18 years old, his parents/legal guardians are the ones who will make the decision exercising their legal representation, as long as they are seeking what is in the best interest of the patient. Of course, the minor should be informed and their opinion should be taken into consideration. Therefore, the criterion that physicians should follow is the one expressed by the parents and, consequently, the patient should be treated for leukemia.

In general, any action which the doctor in charge of the case judges to involve serious risk to the health or life of a patient between 16 or 17 years old requires the consent by representation of the parents or legal guardians, all of which must be registered in the medical record. In the case that the parents do not choose what is best for the health of the minor, again in accordance with Law 41/2002, the case should be brought to the attention of Juvenile Protection Services or the appropriate judicial authority.

This case could be solved in different ways according to the specific laws of each country, as legal age limits can vary. For example, in countries in which the legal age for medical decision-making without requiring the consent of legal representatives is 16 years old, in this particular case, though the patient is just 17 years old, the conservative treatment would have to be followed, as he would be considered a competent patient.

For reflection:



- FILM: Sachs' Disease
- ORIGINAL VERSION: La Maladie de Sachs.
- DIRECTOR: Michel Deville.
- YEAR: 1999
- ANALYSIS: Dr. Bruno Sachs (Albert Dupontel) is a family doctor who works in a rural area in France. He cares for all kinds of patients in his surgery. He usually earns the trust of his patients through active listening and implication in their lives. In addition, he visits them at home when necessary: first aid, terminal patients... and emergency calls. Dr. Sachs ends up "falling ill" because of his extreme implication with his patients, which is referred to in the title "Sachs' Disease". One of Dr. Sachs' patients is a teenage girl who has a conflictive relationship with her mother. A difficult situation for the young doctor.

CASES ABOUT CONFIDENTIALITY

A pillar of the clinical relationship is respect for the intimacy and confidentiality of the patients. Professional secrecy is an ethical, deontological and legal duty of healthcare professionals. It is an indispensable requirement so that the patients place their trust in them. However, there are conflicts related to intimacy and confidentiality that lead to questioning the limits of professional secrecy. It should not be forgotten that confidentiality and intimacy do not refer only to professional secrecy, because they also affect other spheres of the individual. The clinical history is essential for the preservation of confidentiality. Its use is limited to healthcare tasks and in order to respect privacy it is imperative to maintain an appropriate use of such information. Several cases related to confidentiality and intimacy protection are proposed below in which ethical and legal problems difficult to solve are illustrated. They are the following:

- In the first case, a gynaecologist doubts whether she should infringe the intimacy of a 16-year-old woman against her will. The gynaecologist must assess under which circumstances intimacy can be violated, putting at risk the patient's trust, and how by doing this she can alter other values such as respect towards the patient's autonomy or the appropriate use of healthcare resources.
- One of the main conflicts regarding confidentiality arises when there is an inappropriate access to the medical history. In the second case, the healthcare professionals doubt whether to consult the medical record of a citizen for reasons which are not strictly professional.
- Among these exceptions to professional secrecy is the communication of aggression to the Court, for example in gender violence situations. In these cases, conflicts may arise if the aggressor is in the same health centre, if the woman refuses to denounce or if she opposes communicating the injuries to the judicial authority. When violence against a woman occurs, her best interests and her protection are crucial. A case of gender violence is presented with a practical approach.



Lorenzo Vallés, Joanna the Mad (Joanna of Castile).
A sublime rendering of madness.

Clinical case



A 16-year-old patient accompanied by her mother goes to the hospital emergency ward. The patient's mother requests (rather demands) that the gynaecologist on duty examine her daughter since she has spent approximately 24 hours away from home and she wants to know if her daughter has had sex or used drugs during that period. The daughter (patient) refuses to be examined. The emergency gynaecologist on duty asks himself if he should examine the patient against her will.

Ethical analysis

From an ethical point of view, we must bear in mind that the patient's autonomy must always be respected whenever they are competent to make decisions freely and voluntarily. In addition, we must remember that hospital emergency services have the function of serving patients who need assistance in a timely manner, without delay and which cannot wait to be evaluated by primary care or specialist services. Apparently, this case does not seem an urgent situation that must be attended to immediately nor that requires healthcare. Taking into account the principles of distributive justice and the type of assistance requested, it does not seem that meeting the patient's mother's demands would be a good use of health resources.

Furthermore, it does not seem that the examination will produce any benefit to the patient. On the contrary, forcing the patient to undergo a genital examination threatens their privacy, their integrity (as it is in itself invasive and uncomfortable for women) and is, in this case, unnecessary.

Possible courses of action

- Agree to patient's mother's demands: examination is forced.
- Speak with the patient's mother and try to reach an agreement.

- Speak with the daughter (patient) in the first place to make a decision.
- Perform the examination and protect the privacy of the daughter (patient) by not giving the information to her mother.
- Agree to the daughter's request: refusal to carry out the examination.

Recommended courses of action

- From the proposed options, we must choose the one that infringes fewer principles and leads to a resolution as consensual as possible of this family conflict.
- On one hand, it is important to devote time to talk with both the mother and the daughter.
- In view of the ethical assessment, the doctor should not consent to perform the examination since it does not provide any benefit but, instead, violates the patient's autonomy at the expense of her well-being and involves an undue use of health resources.

Discussion

The mother should be asked, in the first place, if she suspects that there may have been a crime or abuse to her daughter since this situation would be the only one that, a priori, could change our approach. If the answer is negative, it would be necessary to explain to her that the examination she is requesting will not provide the information that she wants since it is not always possible to know by a vaginal examination whether her daughter had sex and, additionally, the toxicological analysis would give results that may correspond to the last 24 hours or even before (metabolites of substances of abuse, depending on which one, may be present in the body from 3 days to more than two months after consumption). Furthermore, it is not appropriate to carry out the examination since that would infringe, from an ethical point of view, the autonomy of her daughter who, in the end, has the right to decide. Finally, the mother should be informed that in the event that the examination is performed, the conclusions obtained could not be shared due to the protection of the privacy of her daughter and the obligation of the doctor to keep professional secrecy.

On the other hand, it would be necessary to speak with the daughter and confirm with her that she has not been forced to have sexual relations or suffered any other crime against sexual freedom, clarifying that any information that she gives us will be confidential and will not be transmitted to her mother. It will be necessary to corroborate if she is having an out-patient gynaecological follow-up. If she is not having the scheduled revisions, the patient would be referred to the specialist. Moreover, it would be necessary to confirm that she is not having risky sex and if she is, she might be referred to a family planning unit. If the patient demands some kind of urgent health care at that time, her mother should not be informed regarding it as it is the daughter who will tell her mother if she considers it necessary. Finally, if it is considered appropriate after the conversation with the patient, a referral can also be made to the social workers, mental health center or any other specialist considered appropriate.

For reflection:



- FILM: The Elephant Man.
- DIRECTOR: David Lynch.
- YEAR: 1980.
- ANALYSIS: John Merrick (John Hurt) has monstrous deformities covering his entire body, but especially his head. His physical appearance leads to him be exhibited as a “circus animal” in 19th Century Britain. He is showcased as an animal in touring circuses in the conservative Victorian society. Dr. Frederick Treves (Anthony Hopkins) approaches him and attempts to rehabilitate him, at first for scientific reasons, and later, after getting to know him and “looking into his face”, moved by humane reasons. From then on, Dr. Treves will try to help him and rehabilitate him into society. The film shows how John Merrick’s intimacy is violated constantly.

CAN A MEDICAL RECORD BE CONSULTED FOR THE SAKE OF A THIRD PARTY?

Clinical case

Laura is the primary care physician for Ana, who is a regular patient of hers. Laura and Ana have had a good clinical relationship for years. Ana is divorced and has joint custody of her two children with Andrés, her ex-husband. Andrés, is in a new relationship and he and his girlfriend live together. Ana's children have told her that their father's girlfriend takes a medication called bromazepam for "her nerves". Ana asks the children to tell her about all the medication that Andrés' girlfriend takes. Her children tell her that in addition to bromazepam, she takes another pill called Seroxat (paroxetine). Ana consults Laura to ask what these medications are used for. Laura explains that one is an antidepressant and the other is an anxiolytic medication. Ana becomes very worried. Later on, she requests another consultation, where she asks Laura to look into why Andrés' partner is taking this medication. She wants to know if she should worry about leaving her children with "a mentally ill or unbalanced person". Laura expresses her reluctance to look at the medical records of Andrés' girlfriend. Ana pressures Laura by telling her that if anything happens to her children, she will be responsible for not having done anything. Laura knows that Ana is wrong but, at the same time, she understands Ana's concern and does not want to lose her trust or cause a breakdown in their clinical relationship. What should Laura do? Should she look into the medical records of Andrés' girlfriend?

Ethical analysis

The primary function of a medical record is to provide continuity between different healthcare professionals and work as a tool to ensure proper patient healthcare. Ultimately, it also serves as evidence in the event of a claim or complaint. The medical record includes confidential content about the patient's health, which must be treated responsibly and with discretion. There isn't open access to patients' medical records. Access is restricted to the scope of the professionals caring for the patient: a medical record can only be accessed by the healthcare professionals directly involved in the patient's care.

Furthermore, it is important not to confuse a good clinical relationship with a personal engagement or an excessive willingness to please, which can lead to the

breakdown of a proper clinical relationship. In a proper clinical relationship, there must be set boundaries, defined by the rules of the profession, and there must be a mutual respect. Maintaining trust between a doctor and their patient should not involve breaking professional rules. So it is important for the doctor to know how to set ethical and legal limits that establish their professional competencies, including respect for the confidentiality of other patients. If the clinical relationship is framed within the limits of professionalism (and not a “buddy” relationship), and also respect is guaranteed for the rights of other patients, the clinical relationship of mutual trust will last over time.

In this case, if Laura agrees to Ana’s request (seeking the benefit for Ana and her children), it is possible that she will keep Ana’s trust in the short term, but she will violate the privacy of Andrés’ partner. Furthermore, she would act with malfeasance regarding Andrés’ partner and even Andrés himself. Laura’s professionalism and even the legality of her actions would be put into question.

Possible courses of action

- Expel Ana from the office and ask her not to make any more appointments, thus breaking the doctor-patient relationship.
- Reprimand Ana for making a totally inappropriate request.
- Explain to Ana that her ex-husband’s partner is not her patient and therefore, she cannot give her any information about her.
- Deny Ana’s request. Explain why medical records of those other than a doctor’s direct patients cannot be accessed, and that, even if she could access them, she would not be allowed to give her that information.
- Ask Ana how the children are doing and if there are any signs of inappropriate treatment by Andrés’ new partner.
- Ask Ana how she is doing and inquire about the need for any medication, a mental health consultation or referral to social services.
- Consult Andrés’ partner’s medical record and, depending on the content, tell Ana about it.
- Call Andrés and inform him of Ana’s request.
- Agree to Ana’s request and look at Andrés’ partner’s medical record together.
- Document what happened in the medical record.

Recommended courses of action

- Laura's first action should be to explain to Ana that what she is asking for is not ethical and, in addition, is against legal and professional regulations, so there is no way she can fulfil her request. Laura could also point out how Ana wouldn't like her own medical records to be shown to another party either. It must be made clear to Ana that Laura is adamant on this point.
- Moreover, Ana should know that, even if Laura had this information (if Andrés' partner were her patient), she would not be able to tell her anything because respect, confidentiality and privacy are fundamental to all citizens.
- Regardless of all these explanations, Ana should not sense that her feelings are being neglected. Laura should be empathetic to the situation. It would be advisable for Laura to express to Ana that she understands her concern and that she cares about the well-being of her children, in case there is any alarming sign of abuse.
- Ana's request, the response and any care she receives should be registered in her medical record.

Discussion

- Physicians should limit the access to medical records to their own patients. Access to other people's records is neither ethically nor legally acceptable.
- Requests from other people for information about patients, clinical or otherwise, should not be granted even if justified for the welfare of third parties, unless we have explicit consent from the individual who is affected. The cases in which patient confidentiality can be broken are clearly defined by legislation and by the code of ethics.
- Patients may, on occasion, ask their physician to do something against professional rules. In these cases, the physician must know how to inform the patient of the limitations on medical activities and explain the possible ethical and/or legal consequences that may arise if they cross those lines.
- Refusal of patients' requests should not lead to their departure or a breakdown in the clinical relationship. However, physicians should only treat their patients within their professional duties.
- When a medical action (in this case, a consultation) involves an ethical or legal risk, any action taken must be recorded in the medical record.

For reflection:



- FILM: 21 Grams
- SPANISH VERSION: 21 gramos.
- DIRECTOR: Alejandro González Iñárritu.
- YEAR: 2003.
- ANALYSIS: Among many other facets, the film shows us the conflicts derived from the breach of confidentiality regarding a deceased donor. One of the main characters is university professor Paul Rivers (Sean Penn). Paul receives a heart transplant which produces immune rejection. The professor searches for the heart donor, Christine (Naomi Watts), a woman who was a drug addict and who at present suffers from depression. An accident took the lives of her husband and her two daughters. Paul also finds out who the person responsible for the accident is - Jack Jordan (Benicio del Toro) - who is tormented by feelings of guilt. These encounters will trigger a veritable flood of emotions.

SHOULD A COPY OF A PATIENT'S MEDICAL RECORD BE GIVEN TO STATE LAW ENFORCEMENT BODIES?

Clinical case



Gema goes to the emergency ward and says her husband was drunk and hit her on her left cheekbone. Upon examining her Pedro, the doctor on duty, finds that in addition to her cheekbone, she has bruises on her neck and both arms (Pedro asks Gema if her husband grabbed her, which she confirms). Gema is very nervous and states that she wants to receive medical attention but she does not want to report her husband. The doctor explains to her that, regardless of her decision, he is obligated to make an injury report and send it to the corresponding authorities, in this case the Duty Court. Gema receives medical attention and, upon discharge, is given a copy of her clinical report. When she leaves the emergency room, she is still unsure whether or not to report her husband. A few hours later, two police officers show up at the emergency room. They ask for a copy of Gema's injury report. The doctor does not know if he should give the report to the police, as it may violate doctor-patient confidentiality. Should Pedro give a copy of the injury report to the police?

Ethical Analysis

On many occasions, the actions and reports of medical staff can affect the police and judicial system (possible crimes, complaints, etc.). This can lead to conflicts and doubts about how physicians and healthcare institutions should act. In these cases, a common source of conflict is related to patients' confidential information, i.e. medical confidentiality. It is essential to maintain trust between a patient and their physician in order to have an effective doctor-patient relationship. To this end, the patient must know that the confidentiality and privacy of his or her intimate information will be respected. Protecting patient confidentiality safeguards the trust placed by the patient in the physician and ensures that the physician remains loyal to the patient. This is part of the physician's profession and responsibility. Giving a patient's clinical information to third parties (in this case, the police), violates medical confidentiality and the patient's right to privacy and it could even be harmful to the patient themselves. However, every rule has its exceptions and the duty of medical confidentiality is not absolute. The physician is ethically and legally exempt from maintaining medical confidentiality in certain circumstances. One of them is when facing a possible crime or misdemeanor. The

doctor must collaborate with the justice system in such cases as: reporting injuries resulting from criminal acts, appearing in court as a witness or expert witness, providing the clinical reports required at the request of the court, etc.

In the case at hand, Pedro doubts whether the police's request is an exception to medical confidentiality. In other words, he questions whether violating such an important value (respect for the patient's privacy) is justified by a request for information from the police, also taking into account that he has already sent the injury report to the Duty Court and that he has recommended Gema to file a police report. Therefore, although there is an ethical conflict, it is a legal matter (it is necessary to see if this situation involves a legal exception to medical confidentiality) and this is the sphere in which Pedro's conflict must be approached and resolved.

Possible courses of action

- Give a copy of the medical record and the injury report from the incident to the police officers.
- Only provide a copy of the injury report related to the events being investigated by the police.
- Ask the officers to identify themselves and state the reason for their request.
- Ask the police to provide a written request so that it may be added to the patient's medical record.
- Call the patient for permission to provide the requested documents.
- Find out if a court order is required to release the requested information to the police. If so, explain to the police that a court order is required.
- Contact the hospital's legal services.
- Refuse flatly to provide the requested information.
- Register any action taken in the patient's medical record.

Recommended courses of action

- First, Pedro must ask the police officers to identify themselves.
- In the emergency room they should find out whether a court order and/or written request is required to provide the police with the information they are

requesting. When Pedro consulted the hospital's legal services, they explained to him that a formal written request is necessary to provide the police with the information and for proper documentation in the patient's medical record. However, a court order is not necessary.

- Therefore, Pedro explains to the police that he cannot give them the injury report without a formal written request. He also tells the police that, as the hospital's legal services explained to him, the request must specify which documents are being requested (those pertaining to the incident under investigation).
- If the police make a formal written request, it is advisable that it be verified by the hospital's legal services team before the information is submitted. The hospital's management, in coordination with legal services, should be the ones who deliver the requested documentation, not the physician personally.
- The request and the reason for the request should be registered in the medical record as proof.
- It is advisable for Pedro to register any action taken in the medical record.

Discussion

The patient's medical records must be protected since they contain information about the patient's health. However, there are certain exceptions in which medical confidentiality may be breached, without this implying a breach of the physician's commitment to the patient's care. Despite feeling their trust in the doctor or in the institution can be broken, patients should be made aware that physicians or health-care institutions must breach medical confidentiality when they have knowledge of a possible crime and/or there is a court order for information.

In the event of a possible criminal act, the physician is under obligation to report the incident to the duty judge, who must assess if further legal proceedings are needed. The doctor conveys this communication through the injury report. The report should include the injuries observed (location, size, shape, color, etc.), the account of the facts and the patient's mental state. Mental pathologies should also be considered as injuries. Once completed, the injury report must be sent to the Duty Court and, in addition, this information should be included in the patient's medical record.

When there is police involvement (in response to a complaint or/and at the request of the judge), the agents of the Security Forces and Corps, as a part of their functions as Judicial Police, may request a copy of the injury report or of the

report of medical care received by the patient. In Spain, this procedure is regulated in accordance with the Criminal Procedure Act (art. 796.1) and with the Data Protection Agency (e.g., report of the legal office 0133/2008). The doctor is legally obliged to collaborate with the Judicial Police and provide them with the required information as long as certain requirements are met:

- Identification of the law enforcement officials.
- Submission of a signed written police document stating the reason for the request, to be included in the patient's medical record.
- Only the report or injury report related to the investigated facts will be provided. The complete medical history or clinical data that are not relevant to the police report should not be included.
- It is not necessary for the written request to be accompanied by a court order.

Finally, it should be noted that failure to cooperate with the police may constitute a serious infraction and result in a crime of disobedience.

This case was studied in accordance with the current legislation applicable in Spain. Consequently, its resolution can vary in different legal frameworks.

For reflection:



- FILM: The Net.
- DIRECTOR: Irwin Winkler.
- YEAR: 1995.
- ANALYSIS: When the Secretary of Defense of the United States is told that he has AIDS, he commits suicide. The autopsy reveals that the Secretary did not have the illness. Angela Bennett (Sandra Bullock) is an engineer who works as a software analyst. She leads a solitary life, with hardly any contact with external life except with her mother, who suffers from Alzheimer and who hardly recognises her. Angela receives a hard disk drive from a friend as gratitude for a favour. When she studies it, she discovers that she can access the most important databases of the United States. The Net addresses how data can be manipulated in the present-day world dominated by telematics, internet and social media, the difficulty to control information and, above all, to have the certainty that information is rigorous and reliable.



Fernando del Rincón, Miracle of saints Cosmas and Damian.
How the first graft of history was made.

CASES ABOUT REJECTION OF MEDICAL PROCEDURES

Rejection to medical procedures causes many ethical conflicts. In these cases, the patient doesn't choose the option considered as most recommended from a scientific approach. The rejection by the patient of a healthcare procedure indicated from a clinical point of view can have harmful consequences for the patient which are difficult to assess and assume by the healthcare professionals. However, when considering which is the most beneficial medical action for a patient, it is crucial to respect their autonomy, their values and preferences, which do not always coincide with those of the medical team. The following five cases of treatment rejection are presented:

- For the first one, a case involving treatment rejection with possible harm to third parties is presented. A patient's autonomy has its limits and it must be balanced with other values at stake, such as the well-being of third parties. The case shows how to proceed facing a refusal to be treated in order not to abandon the patient.
- Within treatment rejection situations, the ones in which the rejection is stated by legal representatives of non-competent patients deserve particular attention. A case is proposed of refusal to COVID-19 vaccination for a non-competent elderly person who is a resident in a social-healthcare centre. During the pandemic, many situations like this one arose, which implied a risk for these persons as well as for the rest of the residents. An approach for the management of these cases is proposed attempting to avoid their judicialisation.
- In the third case, a situation of treatment rejection occurs which has consequences affecting the management of healthcare resources. In these cases, an adequate communication with the patient and their relatives is essential to resolving the problem.
- The next case is about the refusal of treatment by an underage patient. This topic has been selected because it is a frequent situation and because of the difficulty it entails on certain occasions. As it is a case of representation by proxy, the best interest of the minor must be sought.
- Lastly, the case of a refusal to treatment that implies a voluntary discharge is posed. The discharge of a patient against the medical criteria is a cause of discrepancies due to the consequences for the patient and additionally the fear of legal responsibilities for the health professionals. In these cases it is necessary to know the steps that should be followed in order to proceed with ethical and legal guarantees.

Clinical case

Case of a 35 year old patient, injecting drug user for about 6 years. He needed to be admitted in the hospital 11 months ago due to pyelonephritis. There is no other background of interest. He is not taking any medication at the moment. Due to risky sexual behavior, he has been regularly monitored by the infectious diseases department for 3 years. The result of the physical examination was that he presented good general condition. Seven months ago, he went to the clinic to collect the results of the STD tests. The results of the analyses showed a positive serology for HIV. After explaining the news to the patient, he was informed about the characteristics of the disease at present, the therapeutic options and the prognosis. In addition, the corresponding complementary tests (CD4 count, viral load ...) were requested and an appointment was booked two weeks later to assess the results. However, the patient did not undergo the new analyses nor attended the scheduled visit two weeks later. The patient had so far come to the scheduled controls sporadically, but at this time it seems that he has completely abandoned the follow-up.

Can the patient refuse the follow-up and treatment of a notifiable disease, which is a risk of contagion to third parties? Should the doctor respect the patient's decision not to be treated? Would the doctor have any additional responsibility in this case?

Ethical analysis

In this case, the main values in conflict would be the patient's freedom of decision, which would be directly confronted with the doctor's care obligation, since he/she understands that with adequate treatment the patient can avoid future damages and suffering to himself and his environment (risk of contagion to third parties). The rejection would imply damaging the patient's health unnecessarily.

If it is the case of a competent patient, it is necessary that the patient consents so that a certain procedure can be performed. If the patient does not give their consent, we would be faced with an assumption of rejection of treatment.

Possible courses of action

- Respect the patient's decision not to be treated nor to continue attending the follow up. Try to contact the patient and re-schedule an appointment for a new informative consultation regarding the disease.
- Once he has been located, evaluate the patient's competence to make medical decisions.
- Find out if the patient continues having risky sexual behavior and if he has a stable partner.
- Offer the possibility of a follow up, even if a treatment is not carried out.
- If he does not want to be treated / followed in our center, offer him the possibility of doing it in another center.
- Inform the Court for involuntary admission and treatment, due to public health risks.

Recommended courses of action

- Locate the patient to try to talk with him again and inform him better about the disease: forms of transmission, evolution of the disease, therapeutic possibilities, evolution of the disease if it is not treated and benefits of the treatment. When informing him, the doctor must make sure that the patient understands the information provided. At that same consultation, if possible, the patient's competence to decide should be assessed.
- It would be important to know if he has a stable partner or if he keeps risky sexual behavior, informing about ways to prevent contagion to third parties.
- In the event that the patient is competent, once he has been properly informed, his decision should be respected.
- If the patient maintains his refusal of medical treatment, he should be offered the possibility of follow-up in consultation, even though he is not treated, be referred to another institution and even the future possibility of palliative measures as the disease evolves. We must not forget that rejection of treatment does not mean abandoning the patient, so the best possible alternatives should be offered.

Discussion

For the rejection to be accepted, the following requirements must be met:

1. The patient must have been adequately informed about his health status, the nature of the disease, the characteristics of the proposed procedure, the consequences of the rejection for his health and the possible alternatives.
2. The patient must be capable and competent to make decisions, which implies that he can understand the information, assimilating it with regard to his values, making a decision and expressing it,
3. It is necessary that there is no risk to the health of third parties.

If these three assumptions are met, the will of the patient should be respected. In any case, it is essential that the information and recommendations given to the patient be clearly collected in the clinical record and that the prophylactic measures are emphasized to avoid contagion to third parties. All the information collected in the clinical history, in addition to facilitating the practice of health care, has great value as a means of proof to document the information that was given to the patient and that the doctor is therefore exempt from liability in case of contagion to third parties. In the specific case that concerns us, there could be a reluctance to accept the diagnosis and, secondarily, a refusal to undergo follow-up and treatment. In most cases of rejection, this is caused by fears of the patient or because the information has not been adequate. For this reason, it is a priority to resume communication with the patient so that they can be better informed and try to appease their possible fears, which may be unfounded.

The course of action would change if we were dealing with a patient with a notifiable disease which, in addition, posed a public health risk, as is the case of bacilliferous tuberculosis. In this case, the risk to third parties is one of the exceptions to the autonomy / freedom to decide of the patient. In such case, an involuntary admission could be incurred due to public health risk. To do this, first the epidemiology department must be informed, which must produce a favorable report. From there, in Spain the institution management, or the doctor themselves in the case he/she were not working at a health center, must request an involuntary admission through the institution responsible for Public Health of the Autonomous Community (Regional Government).

For reflection:



- FILM: *Dying Young*.
- DIRECTOR: Joel Schumacher.
- YEAR: 1991.
- ANALYSIS: Víctor Geddes (Campbell Scott) is an attractive young man who has suffered from leukemia for the last ten years. He hires Hillary O'Neil (Julia Roberts), a nurse who has recently suffered a disappointment in love, to take care of him. Hillary will have to look after him and accompany him to the hospital, especially during his chemotherapy treatments, which have terrible toxic effects. In order to enjoy at least some of the little life he has left, Victor decides to abandon the treatment and lies to Hillary, saying that he has finished the treatment, so they leave together for him to recover. The symptoms inevitably reappear: pains, discomfort, fatigue, night sweats... When Hillary finds out that Victor has abandoned the treatment, she does everything she can to convince him to start it again. She gives him all the arguments she can think of for him to continue, even talking her father into helping her convince him.

Clinical case

Manuel is 78-years-old and has been living in a nursing home for the last two years due to the onset of a moderate dementia which prevents him from being able to take care of himself, needing assistance in basic everyday routines. He is obese, has hypertension, and type 2 Diabetes. Manuel was admitted to the nursing home by court order, as he was considered non-competent to make the decision independently. In March 2021, the nursing home began vaccinations against COVID-19 for all its residents. Manuel, as previously mentioned, is not competent to authorize his own vaccination, so his two children are informed about the vaccine and are asked to consent to his vaccination. After a conversation with the physician, the children state that they do not want him vaccinated and therefore refuse consent for their father to be vaccinated. How should the doctor act now? Should the physician accept their refusal? Or, should he/she vaccinate Manuel regardless of his legal representatives' opinions?

Ethical analysis

In this case, we must take into account both the course of action to perform on Manuel, as well as its impact on the other residents and staff at the nursing home, as the issues of his vaccination can influence them. Manuel is considered to be especially vulnerable due to his cognitive deterioration and, additionally, a patient with a high-risk of suffering a severe Covid as he is over 70 years old and has pre-existing conditions. As Manuel is legally unable to decide for himself, a representative must decide for him, keeping his best interest in mind. The physician is conflicted because he feels that by not vaccinating him the patient's best interests are not being served. If the decision were based on protecting Manuel's health and that of the other residents, then he should be vaccinated. Additionally, health care providers may fear the potential legal consequences should Manuel become infected with COVID-19 and be a source of contamination for other patients and for the staff.

Furthermore, a compulsory vaccination implies a restriction to liberties, in this case of those of Manuel's children. If the vaccination is carried out against the wishes of Manuel's children, the relationship between the physician and the children, or even between them and the centre, may be negatively affected. Herein

lies the ethical conflict: on the one hand, protecting Manuel's health (and that of the staff and other residents) and, on the other hand, the freedom of choice of his children, his present legal representatives.

Possible courses of action

- Ask the children to remove Manuel from the nursing home, indicating that all residents must be vaccinated in order to remain at the center.
- Vaccinate Manuel without his children's knowledge and without registering it in his medical record.
- Vaccinate Manuel. Inform his children, and register it in his medical record.
- Reexamine Manuel to assess whether he is competent to decide for himself.
- Meet with his children to inquire about why they are refusing consent and better inform them about the vaccine and why it is in their father's best interest, aiming to convince them.
- If they still do not agree to consent, refer the case to the appropriate judicial authority to assess the need for forced vaccination.
- Not vaccinate the patient but socially isolate him in the nursing home.
- Not vaccinate and record the reason why in the medical record.

Recommended courses of action

- Ideally, Manuel should make the decision, so he should be reassessed in order to decide whether he is competent. Manuel should be included in the decision-making process as much as possible, ascertaining whether he has an advance directive and if his opinion regarding vaccinations (ie. if he has been vaccinated for other diseases) is known. Only after making sure we cannot know his opinion should we move to have the decision made by third parties.
- When proceeding to take a decision by proxy, this decision must be in the best interest of the patient's health. This is why it is imperative to meet with his children to inquire about their objections to the vaccine and have a motivational interview, trying to convince them that it is best that their father is vaccinated. During this meeting, the physician should invest the necessary time to provide the family with ample information as to why the vaccine is in their father's best

interest and that of the other residents. The interview should allow to assess whether they have adequate information and whether they have understood it.

- If, after that, the children still refuse to give their consent, the case should be referred to the appropriate legal authorities to assess the need for forced vaccination. Manuel is not competent to make decisions, so the best interest for his health must be sought.
- Any actions taken should be registered in the patient's medical record.

Discussion

- The vaccine to combat the COVID-19 pandemic has been developed rapidly, and sometimes new technologies, especially in this context, cause suspicion in part of the population, distrust and rejection. The grounds for distrust and refusal vary: lack of studies on the efficacy of the new vaccines, excessive speed of clinical trials, fear of secondary effects, conspiracy theories of various kinds, etc. However, during a pandemic vaccinations are not only a matter of protecting oneself but also the health of the public. Vaccination seeks to establish “herd immunity”, necessary to protect the population as a whole, to reduce infection and ultimately the morbidity and mortality rates caused, in this case, by the coronavirus.
- Refusal to vaccinate in social and healthcare centers is a healthcare challenge, as it poses a risk to the individual and also to third parties. This scenario is aggravated when the population of these centers is particularly vulnerable, and at higher risk of suffering from a severe infection of COVID-19. In this context, for public health reasons, every effort should be made to ensure that patients are vaccinated. Although judicially mandated vaccines are an extreme course of action, in a case such as the one analyzed, it might be advisable in order to protect Manuel and the other residents at the nursing facility.
- A further question would be to analyze whether centers can make it a requirement that residents be vaccinated. However, in the case studied, Manuel was already admitted to the facility, which is why we did not proceed to analyze this assumption.
- Lastly, it should be pointed out that if a person refuses to be vaccinated and does not live in a care facility, but is determined incompetent, the same actions should apply. However, for people who are fully competent to make decisions, regardless of where they live, their decision should be respected.

For reflection:



- FILM: 2020.
- DIRECTOR: Hernán Zin.
- Year: 2020.
- ANALYSIS: 2020 is a documentary that narrates the events happened due to the COVID-19 healthcare crisis in 2020 and the evolution of the “first wave”. The film is useful to gain awareness of the consequences that an epidemic of a severe infectious disease can have, and therefore, of the importance of vaccination when dealing with this type of pathologies.

Clinical case

José, who is 74 years old, is admitted to a tertiary hospital for bilateral pneumonia as a secondary effect of SARS CoV-2. After three months of hospitalisation, including a period spent in the intensive care unit, and having overcome his acute process, his physician considers the possibility of referring him to a medium-stay hospital with a specialized rehabilitation unit. Prolonged hospitalization has triggered a significant functional deterioration in José, with a decrease in his personal autonomy. His case has been assessed by members of the rehabilitation service team and they concluded that a transfer to this type of hospital would be very positive in order to optimize his care while at the same time enabling José to regain his personal autonomy. José initially agrees with this decision but is very insistent that it be discussed with his children. His daughter Maria, who acts as the children's spokesperson, refuses José's transfer. She believes that if he is transferred "he is being abandoned", that the proposed medium-stay hospital is very far away and that, being of a lower level of care, this could be detrimental to her father. José prefers not to have a confrontation with his daughter, so he accepts what she says. After several conversations, the doctors are unable to convince Maria. In this situation: should the physician in charge keep José in the hospital, or should they force his transfer to the medium-stay hospital?

Ethical analysis

In this case, the ethical conflict results from the fact that the physicians are hesitant because, on the one hand, they don't know if to respect the decision of the patient's daughter, and on the other hand, they believe proceeding with the discharge to a medium-stay hospital/rehabilitation center would be in the patient's best interest. Thus, the freedom of the family (of the daughter) and the best health care option for José are in conflict with one another. In general, medical action and decisions should be aimed first and foremost at seeking what is most beneficial for patients, but the rational use of resources must also be taken into account.

Possible courses of action

- Arrange José's transfer, even despite his daughter's objection.
- Evaluate the possibility of a forced discharge to his home.
- Negotiate with the family and have the care team re-evaluate the case and if it is still considered necessary, proceed with the transfer.
- Explore other plausible alternatives: social-health care residence, home discharge with caretaker and home assistance, etc.
- Ask José what he prefers and act accordingly.
- Interview José and his daughter more in depth to learn more about their concerns regarding the transfer.
- Try to find out what the other immediate family (wife, other children) want.
- Delay the transfer for a few days so that the daughter can digest the news of the decision made by the care team.
- Accept Maria's decision and not discharge José, prolonging his admission until José regains his independence.

Recommended courses of action

- Initiate a deliberating process with José and his family, in which they should be given detailed information on the problems and harms of keeping him in an acute care facility, as well as the advantages of transferring him to a rehabilitation centre. It is possible that part of the reluctance to this transfer could be solved by improving communication and giving more detailed information. The first thing that should be done in this process of information, clarification of doubts/prejudices/fears, is to speak with José, to find out what he prefers. It can also be offered to interview him together with Maria and it would be convenient to incorporate the rest of the family members involved (such as the wife and the other children). It is important to explore the reluctance of the patient or the family to the transfer. In the discussion with the patient and his family, it should be explained that the patient's welfare and the best interests of José are being sought and that the decision is based on medical criteria, not economic or other criteria.
- It may help to delay the transfer so that the family and patient have time to organize themselves and assimilate the information.

- If after giving ample information and relevant explanations, José and his family still refuse the transfer, other plausible alternatives that offer a similar quality of care to the medium-stay rehabilitation centre should be considered, such as a nursing home, discharging the patient to his home with home care and assistance, or finding out if there is a facility similar to the proposed centre closer to the patient's home.
- Re-evaluation of the patient by the care team (ward physicians, rehabilitation specialists) can also be offered, in order to study whether the transfer is really the best option for the patient.
- Once the above mentioned steps have been completed, if there is no medical reason to keep the patient in a tertiary hospital, they should be discharged to a medium-stay hospital or to their home. If this decision is taken against the wishes of the patient and the family, it is advisable that the management of the centre be informed and that it supports the decision of the care team. This forced transfer can be delayed for a few days so that the family can get organized and adjust to the decision.
- If the final decision is to proceed with a forced discharge, the director of the centre, after listening to the patient and the family, must assess whether the patient should remain admitted or whether, on the contrary, he / she agrees with the discharge decision. In the latter case, the patient will be discharged. If the family still disagrees, the proper judicial authority must be informed.
- All the steps and procedures carried out should be properly justified and must be registered in the patient's medical record.

Discussion

In order to act, it is essential that we know José's opinion on the matter. Except in situations of incompetence, it is the patient who receives the information and makes the decisions. José may not object to the proposed transfer and might be simply taking advice from his daughter. If José feels it is appropriate, a discussion can be held between himself, his daughter Maria, and the rest of the family, who may not be adequately informed. When there is resistance to a medically justified decision, it is imperative to know the concerns, fears, needs, and possible prejudices of those affected. By knowing and understanding these needs, fears, and available options, José and his family will be able to choose what is best according to their needs and circumstances.

Nevertheless, listening to and deliberating with the patient and their family does not mean that healthcare facilities should necessarily submit to the demands of a patient or their family if these demands are capricious or may harm the patient. It is important to keep in mind that prolonged admission to an acute hospital poses a risk to the patient's health, due to the risk of iatrogenesis, care-related infections, and other types of incidents common during long-term admissions. In short, to remain in a tertiary hospital is not always in a patient's best interest.

In addition, the fact that the hospital bed has an economic cost for the institution cannot be overlooked and, in addition, it may be necessary for another patient. Extending a hospital stay unnecessarily violates distributive justice because it implies poor management of healthcare resources: as long as José occupies that bed, it is not available for other patients who may need it. Moreover, even in situations where there is no need to free the bed, keeping a patient in the hospital without medical criteria is a misuse of available resources.

As a last resort, it may be necessary to assess the possibility of a forced discharge. In this case, the management of the centre will be informed of the circumstances of the case. After listening to the patient, if the professional in charge still considers that the patient should be discharged and transferred (even if the patient persists in their refusal), they will inform the proper court of guard. This option should be considered as an extreme alternative that should be avoided as it implies the loss of trust in the professionals involved and an irreversible rupture of the care relationship.

For reflection:



- FILM: The Death of Mr. Lazarescu.
- ORIGINAL TITLE: Moartea domnului Lăzărescu.
- DIRECTOR: Cristi Puiu.
- ANALYSIS: This film narrates the journey of Dante Remus Lazarescu (Ioan Fiscuteanu), gravely ill, through the healthcare system. Mr. Lazarescu is a lonely retired engineer from Bucharest. An alcoholic, he lives in appalling unhygienic conditions. One night he starts having a headache and vomits. His neighbours call an ambulance to take him to hospital, where the medical team will suspect he has, in addition to neurological and digestive disorders, a disseminated cancer. Dante is seriously ill and needs an urgent neurosurgery intervention but he is rejected and discharged from every hospital because they are overcrowded and they can't look after him appropriately. This Romanian film shows how absurd bureaucracy can be and how dehumanised medicine can sometimes become, most of all when the patient lacks the tools to defend him or herself. But, above all, it demonstrates how important it is to have an adequately organised and managed healthcare system.

Clinical case

Juan is 2 years old. His parents brought him to out-of-hospital emergency service with a high fever of 39.5°C and a 6 hours time of evolution. He showed symptoms of conjunctival hyperemia and ocular discharge. His parents revealed that they had not vaccinated either of their two children (neither Juan nor Elisa his sister, who is 3 years old). They also had not started the registration of schooling process, nor had either child attended nursery school. Upon physical examination of his general condition, it was observed that the patient had a certain degree of prostration, scattered petechiae, several Koplik's spots and a non-productive cough. Given Juan's general physical state it was decided to admit him into the hospital. In the hospital he was diagnosed with measles, after a worsening in development: more Koplik spots on the oral mucosa, high fever with associated convulsions and a low level of consciousness. Admission into the ICU was then required due to his low level of consciousness and his affected respiratory system. Two months later, Juan was released with a diagnosis of encephalitis and pneumonia caused by the measles, with long term effects on his central nervous system. During Juan's stay at the hospital, doctors recommended that his parents vaccinate his sister Elisa. However surprisingly, his parents refused to have their child vaccinated. The pediatricians learned that the mother (the primary representative, the father had little say) had been diagnosed with a psychiatric disorder several years before, however her exact condition and whether or not she was being treated was unknown. The pediatricians doubted her ability to understand the possible consequences of refusing the vaccination, in this case the vaccines included in the mandatory vaccination calendar. That's why they brought this case to the Ethical Committee with the following question: should the rights of parents to decide about whether to vaccinate their children (a preventive measure) prevail over the protection of the health of a minor (and virtually, of the community)?

Ethical analysis

In the case above we face the rejection of medical proceedings, as the parents rejected a scientifically proven medical preventive measure for their children, in

this case the vaccines included in the vaccination calendar (specifically the measles). This refusal could have caused an avoidable damage to the health of one of their children (Juan) and, in addition, the possibility of their daughter Elisa also suffering from the measles if not vaccinated. It is evident that there is a conflict between two values, on the one hand, a parent's right to choose what is best for their child (as legal representatives) and on the other hand, the protection of the health of a minor.

With regard to the parents rights, their autonomy certainly has limits, as is the damage to their children's health. Parents must decide what is most beneficial for their child, so in cases where the doctor sees that this is not happening, they should use all means possible to protect the health of that minor. Regarding the protection of a minor, in Spain, Law 41/2002 regulating patient autonomy establishes in its article 9.3.6 the following: *"In cases in which consent is to be granted by the legal representative or related persons for family or factual reasons [...], the decision should always be made based on what is best for the life or health of a patient. Decisions that are contrary to these interests must be brought to the attention of the judicial authority, directly or through the Public Prosecutor's Office [...]"*

Possible courses of action

- The rejection of vaccinations by parents is lawful, and therefore, once they are informed, it must be respected.
- Ensure that parents have appropriate information and a good understanding about vaccinations. If not, it would be necessary to speak with the parents again to insist on the reasons that support vaccination.
- Try to speak to the father separately, in the case he might have a different opinion and therefore may be able to help us convince the mother.
- Bring the case to the Prosecutor's Office for child protection or the Duty Court with the aim to vaccinate Elisa against her parents will.
- Vaccinate Elisa against her parents will and also inform the Prosecutor for child protection or the Duty Court.
- Carry out an assessment of the mother's competence for decision-making, in this case regarding the refusal to vaccinate her children.
- Bring the case to the attention of a social worker and the family doctor for a subsequent follow-up and family support if needed.

Recommended courses of action

- Healthcare workers should do everything possible so that the parents choose to vaccinate their children, because, not only is it positive for them, but also for the community. In order to accomplish this, we should first ensure that the information the parents receive about vaccinations and their understanding regarding them is suitable. If not, speak with the parents again to insist on the reasons that support vaccination. All efforts must be put in speaking to the parents and informing them of the consequences of their decision not to vaccinate. The hospitalization of Juan with a serious illness due to not being vaccinated is a good opportunity to refute their arguments, which lack a scientific basis. If necessary, the available scientific evidence should be provided.
- Try to speak to the father separately, in case he has a different opinion, and therefore might be able to help us convince the mother. If it is observed that the father does not have a clear opinion on whether to vaccinate his children or not, we can still try to convince him so that he may also assist us in convincing the mother as well.
- If there are doubts about the mothers competence to make decisions, an assessment of her decision-making should be made. Namely, to evaluate if the mother has the capacity to make the decision not to vaccinate her children. There are tests and scaling systems to assess this; if there are any doubts, you can consult a psychiatrist. If it is determined that the mother is not competent to make the decision, then the responsibility would exclusively rest with the father to make it, as he seemingly offers no doubts regarding his competence to make decisions.
- If after all this, they persist in refusing the vaccination, as long as there is not a public health crisis (an epidemic or similar), parents would initially have the right, under the current framework of Spanish legislation, to refuse vaccination. However, given that this is considered a high risk case of infection for their daughter Elisa, who is 3 years old, (due to her living with Juan and his parents, who may also be infected) it would be treated as a special health risk case for Elisa. Therefore, being a minor in a special health risk case, given that it is uncommon to refuse vaccination and in compliance with the Spanish Law of Autonomy, the case should be brought to the attention of the judicial authority, so that they may assess what decision best suits the greater health benefit of the child.

Discussion

Compulsory vaccination has caused the opposition of those who support the individual's right to decide, defending the rights of parents to raise their children according to their values. Presently, between 5 to 10% of parents are against vaccinating their children. At this stage, it is hard to find a balance between the right to choose (not to vaccinate) and the protection of the community, especially of those who are most vulnerable. To date, the Spanish regulatory framework considers mandatory vaccination to be against fundamental rights: the right to freedom, to religious beliefs, to one's own ideas..., therefore it cannot be obligatory to vaccinate unless there is a health crisis, such as an epidemic that puts collective health at risk. However, it must be taken into account that this case has been studied in accordance with the current regulatory framework in Spain.

So that a right such as vaccination can be voluntary, society must provide some guarantees, among which the importance of an appropriate education stands out. The decision to refuse vaccination must be based on knowledge, not on unfounded prejudices. The provision of incentives has also been postulated, such as economic grants (very questionable) or other types, like having an obligatory calendar in primary schools, nurseries, and universities, prohibiting children who have illnesses preventable through vaccinations to attend education centres, etc. It has also been suggested that tutors who refuse vaccinations sign a consent form with their refusal. All of these are debatable measures.

For reflection:



- **FILM:** Kavros, a History of Bioethics.
- **ORIGINAL TITLE:** Kavros, una historia de la bioética.
- **DIRECTOR:** Benjamín Herreros.
- **YEAR:** 2021.
- **ANALYSIS:** This documentary film approaches the History of bioethics and its main conflicts. Made during the height of the COVID-19 pandemic, it deals with the problem of COVID-19 vaccination refusal.

Clinical case

Juana, a 17-year-old, has come to the hospital because of weight loss that started three years ago but has worsened increasingly over the last few months. Her habitual weight during the last year has been 50kg, but during the lockdown, she dropped to a minimum weight of 42kg. Juana reports eating 3-4 small meals a day, doing exercise at home, and having remedial behaviours for when she feels she has eaten too much. At the hospital consultation, her BMI shows 13.67 Kg/m² (height 1.60 m and weight 35 kg), so she is admitted to a specialized unit. Juana, who came to the hospital accompanied by her mother, states that she has not been diagnosed with anorexia nervosa and that she doesn't suffer from this pathology, rather her condition is due to a case of extreme anxiety due to the pandemic and that she has even gained back 2kg. 72 hours after admission Juana starts having anosmia, without presenting any other symptoms. An RT-PCR for COVID-19 is performed and turns out positive, so she is then transferred to the COVID ward. Her mother is advised that she should accompany her during the admission process to ensure proper care in the isolation conditions required for COVID infections. The mother is then informed of the current situation and the possible risks she faces. In light of the situation, Juana's mother proposes that she be discharged voluntarily. The risks of being discharged are explained to her, highlighting that the discharge would be against medical advice. The following day, the family reiterates that they want a voluntary discharge. Given the situation: what should the doctors treating Juana do? And what should the hospital where she is admitted and being treated do?

Ethical analysis

In this case, two problems must be distinguished:

- The mother's request for the voluntary discharge of an underage patient, aged 17, with a compromised clinical situation (due to anorexia) may put the minor's health at risk if the patient is discharged.
- The assessment of whether the admission of the patient is of a psychiatric nature for an eating behavior disorder (ED), in which case the patient may not

be competent to make a decision regarding admission, or whether the admission is a general hospitalization to address the patient's dual pathology (ED, which is what justifies the admission and COVID).

In this case, the autonomy of the family and, possibly, of the patient Juana, come into conflict with the patient's care (the possible clinical benefit), as a discharge could be detrimental to the patient. ED cases are very complex because they may compromise the patients' ability to make decisions and, therefore seek what is in the best interest of their health. On the other hand, if physicians, seeking the clinical benefit of the patient, act against the will of the patient and her family, it may break their trust with the doctor and even with the institution.

The application of legal resources (to litigate the case) should always be an extreme course of action. It is better to try to reconcile the issues at stake (the family and patient's freedom on one hand, care of the patient on the other) without having to go to court. Resorting to a judge means giving up the chance of finding a course of action that respects the values at stake, and moreover, may break the trust between the healthcare team and the patient and her family.

Possible courses of action

- Accept the mother's request, without even knowing what Juana's opinion is regarding her voluntary discharge.
- Interview Juana, who is 17 years old, regarding her opinion and if she wishes to be discharged, proceed with the process.
- Ask Juana her opinion but regardless what she wants follow the mother's wishes.
- Try to convince Juana and her family that it is best she remains in hospital.
- Wait to see how her COVID-19 symptoms evolve before proceeding with the hospital discharge and explain it to the family.
- Offer the patient and her family more care support from the hospital to ensure that the patient continues to be an in-patient.
- Proceed with the discharge and ensure a close outpatient follow-up. Readmit Juana when she isn't required to be in isolation due to COVID-19.
- Bring the case to the attention of the proper judicial authorities

Recommended courses of action

- The physicians in charge should know what Juana's opinion is, since she is 17-years-old and surely mature enough to understand the situation and express her wishes.
- A careful deliberation process should be carried out with the family and Juana. This process should aim to provide Juana and her family with as much information as possible. They should be aware of the possible risks of discharging her (and also of remaining admitted), as well as the benefits and risks of any possible alternatives being considered. If necessary, communication expert psychologists should be involved in this information and deliberation process.
- If, after trying to convince Juana and her family that she should remain admitted to the hospital for ED, they still would like for her to be discharged; then close home monitoring for anorexia should be considered as well as admitting Juana when she is not required to be isolated due to COVID-19. Leaving Juana in isolation in hospital against her and her family's wishes, could also be detrimental.
- However, if this close monitoring (and subsequent admission) in the best interest of the minor cannot be ensured, then the case should be brought to the attention of the judicial authorities. If, in addition, her admission is considered to be primarily a psychiatric one, the Court of First Instance should be notified as a matter of urgency for involuntary commitment. This last step is an extreme course of action that should be avoided whenever possible.

Discussion

In any case, the decision they make must be defined by legislation. Regarding voluntary discharges, in Spain it will be necessary to act in accordance with the provision of Law 41/2002, regulating patient autonomy, and Law 26/2015, amending the system for the protection of children and adolescents. Both these laws establish that in patients under 18 years of age where there is a risk to health or life, the decision does not correspond to the minor, but rather to the parents or legal guardians. In any event, the child's decision must be heard and taken into account. In our case, therefore, it is the parents who must make the decision, once we have heard and taken into account Juana's wishes. If the parents make a decision that is not in the best interest of Juana's health, in Spain the Law states

that the Juevnielle Protection Prosecutor's Office or the Court of Guard must be informed in order to establish what the best treatment for the minor is.

Regarding the possible involuntary admission (in the case of an ED which makes the patient incompetent to decide), article 763 of the Spanish Civil Procedure Law specifies that involuntary psychiatric admissions must be reported within 24 hours to the corresponding Court of First Instance. In this case, even if the parents agree with the admission, the Court of First Instance must be notified. After that, the Court will have 72 hours to ratify the necessity of the patient's admission.

This case has been studied in accordance with the current Spanish legislation, therefore its resolution may vary in other regulatory frameworks.

For reflection:



- FILM: To the Bone.
- DIRECTOR: Marti Noxon.
- YEAR: 2017.
- ANALYSIS: Anorexia is one of the most difficult to treat rejection situations, in this case to food. In this film, Ellen (Lily Collins) is a 20-year-old woman who suffers from anorexia nervosa. Her family doesn't know what to do, and they book an appointment with a doctor who follows not very orthodox methods. Ellie accepts a group treatment with other persons who suffer from eating disorders. She will have to face the real risks and problems of her illness.



Pieter Brueghel the Elder, The Triumph of Death.
No one survives.

CASES ABOUT END-OF-LIFE SITUATIONS

One of the spheres of healthcare that produces the most ethical conflicts is the handling of the end of life. The limitation of therapeutic efforts, palliative care (in the healthcare of end-of-life situations, care and allaying of suffering gain special relevance) or the assistance to death (euthanasia and assisted suicide) are examples of highly conflictive situations, without forgetting that death itself is normally a complicated moment, most of all if it is seen as a failure of medicine. In this case, the frustration of the medical team and the family can complicate the assistance, the accompaniment and the mourning after the decease.

- One of the situations that create conflicts in healthcare at the end of life is palliative sedation. The first case selected is about a patient in a terminal situation with an important degree of suffering, in which sedation is proposed. The case presents the concept of palliative sedation to clarify when it can and should be carried out.
- The second case is complementary to the previous one. Palliative sedation is proposed once again and the possibility of adding the limitation of therapeutic efforts is introduced. In order to make these decisions, the wishes of the patient and their family must be taken into account. But it mustn't be overlooked that sedation has precise indications which must be known by the professionals that work in end-of-life care.
- Euthanasia, which is legal in Spain, generates many difficulties in end-of-life healthcare because, among other motives, it raises ethical doubts in many professionals. A case is presented to help distinguish euthanasia conceptually from other situations of end-of-life medical aid, such as palliative sedation or limitation of therapeutic efforts.
- The last case refers to the issue of advance directives, also known as living will, last will or last wishes. It explains what they are and it clarifies the main doubts that arise when carrying them out within end-of-life healthcare: how and when they should be registered in order for them to be valid; what their content can be; when they can be applied and how they are fulfilled, especially if the relatives disagree with them.

Clinical case

8 3-year-old male patient. He was diagnosed 3 years ago with colon cancer with a good quality of previous life. The background of interest in his clinical record includes cholecystectomy, dyslipidemia, hypertension and ischemic heart disease. He also has mild COPD. After the diagnosis a hemicolectomy was performed, and he began chemotherapy for the oncological treatment. In one of the reviews a hepatic metastasis not susceptible to surgery was observed. The oncological treatment was optimized after being evaluated by the committee of digestive tumors, but after three months, again in a follow up consultation, his doctor observed an increase of the hepatic metastasis, as well as the appearance of a metastatic tumor in the right iliac blade and another one at the bottom of the right lung. The patient presented associated bone pain, minimal effort dyspnea and intense asthenia. The patient was informed of the absence of response to active treatment and palliative care assessment was requested, whose specialists began to follow and treat the patient. Six months later there was a worsening: deterioration of the general state of the patient, which made him more dependent, and become an overload for the family. The palliative care team has gradually added doses of morphine to control dyspnea and pain.

Three months later, the patient and his family go to the emergency room due to severe dyspnea. He is admitted to the oncology area. Upon entering the ward, the patient comments with the doctor in charge of the case that the palliative care team has talked with him about possible palliative sedation in case of refractory symptoms (those that do not respond to optimized treatment). He also expresses guilt for being a burden to his family, as well as being tired of the whole medical process he is living. After expressing all these thoughts, the patient suggests to the doctor that it might be best to sedate him. To sedate this patient at that time creates a lot of conflict to the oncologist. He is not sure if sedation is indicated and he does not want to be “producing the death of the patient with sedation”, admitting also being afraid of the possible legal issues if he sedates him. Should this patient be sedated?

Ethical analysis

What is sought with palliative sedation is the greatest possible comfort for terminal patients suffering from refractory symptoms, using the necessary dose

to achieve symptomatic control. In the case presented, the wishes of the patient, who requests to be sedated, and the maintenance of his life at all costs, come into conflict. Not forgetting the fears to the possible legal issues.

Possible courses of action

- Respect the decision of the patient and sedate him with high doses of sedative drugs so that he does not suffer, even if it leads to the death of the patient.
- Carry out a complete assessment of the patient's symptoms, as well as of the possible approaches.
- Optimize the palliative treatment and if necessary, sedate the patient with the proportional dose to his symptoms.
- Evaluate the patient's competence.
- Integrate the family in the decision-making process.
- Intubate the patient while the oncologist decides what to do.
- Not sedate the patient because it is not indicated, and sedation can also cause his death.

Recommended courses of action

- In these situations, the first thing that should be done is to verify the patient's competence, which seems intact in this case, as well as to make a full assessment of the case: information received by the patient, prognosis, current and foreseeable symptoms, possible therapeutic options, and so on.
- In this evaluative process it is essential to give ample information to the patient, check if the symptom control can be improved and provide the means to allay the patient's discomfort, including the feeling of guilt. It must be analyzed if the treatment is optimized and, if not, the palliative treatment should be optimized.
- After all this, if he continues to be symptomatic and still says that he prefers to be sedated instead of suffering from the symptoms as he does, it would be necessary to initiate a sedation with the necessary drugs in proportional doses to the patient's symptoms. If the doctors responsible for the case lack experi-

ence in palliative sedation, they should consult with medical experts in palliative care.

- If the doctor and the patient come to agree on sedation, it is important to try to integrate the family into the decision and offer, both to patient and relatives, the possibility of psychological and / or spiritual support if they consider it necessary.
- In this process, the doctors must show their willingness to answer any questions or needs the patient and family may have regarding sedation.
- The entire process must be registered, as complete as possible, in the clinical record.

Discussion

Classically speaking, the principle of double effect is used to argue the relevance of palliative sedation, since it can shorten life as a side effect (double effect) of sedation. One of the differences of sedation with euthanasia is that the goal of sedation is not the death of the patient, but to seek their well-being.

Regarding possible legal or deontological problems that may arise, it must be taken into account that the clinical guidelines and palliative care protocols not only allow for sedation, but also point out that it is a good medical practice when indicated. As a matter of fact, in Spain both the Medical Ethics Code and the current legislation consider sedation as a part of the care to terminal patients, so it is the doctor's obligation to suggest it when it may be suitable and, when appropriate, perform it. With sedation (and in general with palliative care) therapeutic obstinacy (previously known as "therapeutic harassment") is avoided, which is what would happen if the patient is intubated (one of the options proposed), without forgetting that this option was also against the wishes of the patient.

This case has been studied in accordance with the Spanish current legislation, therefore its resolution may vary in other regulatory frameworks.

For reflection:



- FILM: *Steel Magnolias*.
- DIRECTOR: Herbert Ross.
- YEAR: 1989.
- ANALYSIS: Palliative sedation is a part of the care of patients in end-of-life processes and palliative care. Shelby Eatenton (Julia Roberts) is a young woman who suffers from diabetes with many associated health issues. She decides to have a child against the doctors' and her mother's opinion. Pregnancy and giving birth put her in a life-threatening situation. Shelby receives a kidney transplant. Unfortunately, the surgical intervention goes wrong and she enters in a state of refractory coma, with no response to any of the treatments prescribed. Her mother (Sally Field) decides to discontinue the life-support measures and opt for a palliative care. This hard decision leads to the mother being alone with Shelby at the moment of her death, The rest of the family cannot bear the situation.

Clinical case

8 1-year-old woman diagnosed with severe vascular dementia, deep vein thrombosis, anemia and hip fracture 4 years ago. The patient has been institutionalized in a nursing home since the date she suffered the fracture. During the last year she has suffered a notorious loss of autonomy and worsening in functional impairment, with a score in the Barthel Index of 20 and a result of 10 points in the MMSE. She is disconnected from her environment, not being able to recognize her children or grandchildren (she presents severe alteration of memory that affects her daily tasks). Scarce communication, which is usually incoherent. As a consequence of her state she has required containment in a wheelchair to prevent possible falls for many years. In addition, 5 months ago, and in agreement with the family, it was decided to place a nasogastric tube (NGS) due to inability to feed her, requiring upper limb containment to prevent her from removing it. In the face of contention, she reacts with anxiety and a certain aggressiveness, which is why it has been necessary, moreover, to prescribe sedatives in the case of agitation. The family goes every afternoon to see the patient and has been explained her poor prognosis.

The family (husband and two children) manifests to the doctor of the afternoon shift their desire for palliative sedation, given that both the disconnection of the patient with the environment and her dependence are total. The relatives say that they no longer recognize her and that, lately, they also find her very sleepy because of the medication. They add that she would have wanted a palliative sedation if she had seen herself in the current situation, since she had stated on numerous occasions that “if she were to lose her head, there was no point in living and she did not want to be a burden for the family”. The doctor of the afternoon shift has doubts about the legality of palliative sedation, so he takes the case to the weekly session they have at the residence, where he raises the following questions: is it correct to sedate this patient? If sedation is not indicated: how should the medical service act with the patient and her family?

Ethical analysis

In this case, the respect of the autonomy of the family members (and possibly of the patient) with what is considered good clinical practice come into conflict,

since palliative sedation in this case is not indicated. If it were to be carried out, since it is an action that is not indicated with negative consequences (the death of the patient), the health professionals who practiced that action, if sued, could be prosecuted and criminally convicted.

In these situations, it is important to explain to the family members the different options and to maintain trust in the relationship with them, elucidating the commitment of the professionals with the patient's care.

Possible courses of action

- Fulfill the wishes of the family members (and perhaps the patient) and start palliative sedation.
- Explain to the family what palliative sedation is (indication, drugs, dosage, consequences).
- Explain to the family the possible legal consequences in the case of performing a non-indicated palliative sedation.
- Review the patient's condition and the measures that have been taken in order to readjust the treatment (drugs, pharmacological and physical restraints) to seek the patient's best comfort.
- Propose alternatives to the NGS.
- Completely remove physical and pharmacological containment.
- Inform the Court of Guard about the request of the family so that they can decide if it should be performed or if there is a need of judicial investigation of the family.

Recommended courses of action

- The first step would be to adequately inform the family members (and the afternoon doctor who had doubts about how to handle the case) about what palliative sedation is, its indications and how it is performed.
- After that, we would have to propose a Shared Care Plan (deliberative process of planning of decisions) with the family that includes the adaptation of all the measures to the current situation of the patient. This plan may include:

- Readjustment of the medication.
 - Assessment of the risk of falling to see if the physical and pharmacological restraints can be removed.
 - Propose alternative measures to NSG, such as percutaneous endoscopic gastrostomy (PEG).
 - Present the possibility of the limitation of therapeutic efforts (LTE) in the case of acute complications (infections or other complications) and also with regard to the NSG (withdrawal of the tube).
- Any of the decisions taken from the therapeutic point of view as well as the agreements reached between the healthcare team and the family members for current and future care must be registered in the clinical record.

Discussion

In this case, palliative sedation would not be indicated as the requirements to apply it are not met: terminal patient with symptoms refractory to conventional treatments. Although she could be considered a terminal patient (the case should be evaluated with palliative care specialists), the application of palliative sedation is not appropriate since she does not have refractory symptoms.

If sedation were applied without it being indicated, it would involve committing a crime included in the Spanish Criminal Code (article 143) and it would also pose a deontological violation.

If the limitation of therapeutic efforts (LTE) is performed, it must be explained that the LTE does not involve an abandonment of the patient. When the LTE is performed, palliative measures are prescribed so that the patient does not suffer, and, eventually, a palliative sedation may be necessary (terminal state and refractory symptoms). But at the present time palliative sedation is not indicated. It must also be explained that LTE is an accepted action from a clinical, ethical and legal point of view, as well as a properly applied palliative sedation is. Whenever possible (in this case it is) the decision of LTE must be agreed upon by the family, seeking the best for the patient.

This case has been studied in accordance with the Spanish current legislation, therefore its resolution may vary in other regulatory frameworks.

For reflection:



- FILM: The Sea Inside.
- ORIGINAL TITLE: Mar Adentro.
- DIRECTOR: Alejandro Amenábar.
- YEAR: 2004.
- ANALYSIS: Ramón Sampedro (Javier Bardem) is a seaman who is quadriplegic due to an accident on the beach. He wishes to have euthanasia applied to him, to be helped to die, but euthanasia and assisted suicide are illegal. He seeks the support of doctors and authorities, but he does not find response. Moreover, the court also denies him the right. Facing such opposition, a group of friends helps him to die. He himself will take the potassium cyanide that his friends have prepared between them.

Clinical case

Luisa is an 84-year-old patient with severe COPD and very severe pulmonary hypertension (PSAP 80-90). She is diabetic, hypertensive and has had several coronary events, so it is common for her to present episodes of congestive heart failure (LVEF <20%). She is currently hospitalized for a respiratory infection and heart failure. She has a low cardiac output, with hepatic failure related to her congestive heart failure. Luisa is not competent to make decisions at this time. Given the refractoriness to the prescribed treatment (antibiotics, bronchodilators, diuretics) and poor symptomatic control (significant dyspnea at rest, delirium with episodes of psychomotor agitation), symptomatic treatment with boluses of morphine and neuroleptics is initiated. Luisa's physician believes she is in a terminal situation, and considers these to be the last days of life, with poor symptomatic control. After discussing this with the rest of the team, they all agree to suggest the possibility of palliative sedation to the family. Luisa's husband, a retired physician, refuses sedation. He justifies his refusal by being "against euthanasia". He states: "I don't want my wife to die from euthanasia, medicine is for something else". However, Luisa's daughter is in favor of palliative sedation. She says she is aware of her mother's dire prognosis and does not want her to die in pain. During a conversation with the family, the doctor explains how Luisa is suffering from refractory symptoms and the daughter tries to convince her father to change his mind. The husband, during the interview, rebukes the doctor exclaiming "how can you live with yourself by practicing euthanasia and killing patients?". Deeply affected by the conversation, Luisa's doctor begins to have doubts and wonder if he is really considering euthanasia.

Ethical analysis

In Spain euthanasia was legalised in 2021 through the approval of Organic Law 3/2021, on March 24th, regarding the regulation of euthanasia, representing a new paradigm for healthcare, because it raises new conflicts and ethical and legal doubts. Putting aside the myriad of problems arising from the law, the first thing healthcare professionals should be clear about is the difference between palliative care, which aims to improve the quality of life for the terminally ill, and euthanasia, which seeks to aid in the dying of patients who may or may not be terminally ill. Euthanasia is a

medical procedure performed at the voluntary request of the free of will patient where a physician administers a drug to help a patient die. Spanish law considers this assistance in dying when a patient suffers from serious and incurable diseases, or in cases of serious, chronic and incapacitating illnesses. In medically assisted suicide (MAS) it is not the health professional who administers the lethal drug, but the patient themselves after receiving a medical prescription.

The legislation on euthanasia approved in Spain takes into account the following requirements for requesting aid in dying:

- Being 18 years old or over.
- Having a Spanish nationality or having been a resident in Spain for at least the last 12 months.
- Being competent to make decisions
- The request must be made voluntarily and repeatedly. Besides verbally, it must be made in writing and on two different occasions (which must be at least 15 days apart).
- The applicant must have received verbal and written information about his or her illness, about the possible alternatives and the palliative resources available, as well as the resources he or she may need due to his or her possible dependency situation.

Luisa's case does not meet the requirements for euthanasia, but for limitation of therapeutic efforts (LTE), palliative care and possible palliative sedation.

Possible courses of action

- Withdraw the morphine and implement all possible active measures to try to prolong Luisa's life as much as possible.
- Sedate the patient with the daughter's consent, even without her husband's approval, because it is in her best interest to do so.
- Request authorization to perform palliative sedation from a duty judge.
- Conduct an in-depth interview with the husband in which the clinical situation of the patient is detailed; the irreversibility of the condition and the refractoriness of her symptoms... as well as to learn more about his reasons for refusing palliative sedation.
- Explain to the husband that what is being considered is palliative sedation and not euthanasia. Afterwards, allow him a reasonable amount of time to reflect and make a decision.

- If the patient's clinical situation permits it at some point, ask Luisa about her preferences.
- Ask the family what Luisa would have wanted in this situation; if at any time Luisa had expressed her wishes as to how she wanted the end of her life to be.
- Have an internal consultation with the palliative care team to assess the case and help in its approach.
- Assess the case in a clinical session to explore possible therapeutic alternatives.
- Register the actions performed in the medical record.

Recommended courses of action

- Since this is an non-competent patient who, as far as we know, has not left a written advance directive, the family should be asked what Luisa would have wanted in the current situation. It is important to know if at any time she had expressed her wishes as to how she wanted the end of her life to be, because if so, Luisa's wishes should be respected.
- Conduct an in-depth interview with the husband about Luisa's clinical situation. The irreversibility and refractoriness of her symptoms should be discussed at length.
- In this interview, the husband's reasons for refusing palliative sedation need to be explored, as he seems to be confused between euthanasia and palliative sedation. It is important that it is clear to him that what is being considered is palliative sedation and not euthanasia. While euthanasia and medically assisted suicide (MAS) are forms of aid in dying, in palliative sedation the goal is to relieve the patient's refractory symptoms. It should be clear that, although both procedures are legal in Spain since Organic Law 3/2021 came into effect, the procedure, the prescription and the objective they seek are different.
- After explaining all this, the husband should be given a reasonable amount of time to reflect and make a decision. During this time of reflection it is important for the husband to talk to the people closest to him, in this case his daughter.
- A consultation with palliative care specialists should be carried out as the palliative care team should be involved in the entire process.
- While the husband and other relatives make a decision regarding the palliative sedation, palliative care should be maintained to prevent Louisa from suffering unnecessarily.

- If the husband and daughter finally refuse the palliative sedation, the physicians in charge should assess, for the sake of the patient's best interest, the possibility of requesting it to the corresponding duty judge, understanding it must always be the last option.

Discussion

Luisa's case does not meet the requirements of euthanasia, since, for the time being, there is no request for assistance in dying on the part of the patient. Therefore, the approach for this case would not change in countries where euthanasia is not legally approved, as it is really not a case of euthanasia. This is a terminal patient in the last days of life for whom decisions have already been made to limit therapeutic efforts (she has not been admitted to the ICU) and for whom, in accordance with good clinical practice, palliative management has been initiated. In this case, since the patient has refractory symptoms despite the symptomatic treatment prescribed, palliative sedation should be considered to ensure the patient's comfort. Unlike euthanasia, palliative sedation's use is not intended to assist in dying, but to treat refractory symptoms, even if this may result in the possible shortening of a patient's life.

In any case, it should not be forgotten that in the case of terminally ill patients, decisions should be aimed at respecting their preferences. If possible, Luisa's clinical condition should be explained to her as well as the possible therapeutic alternatives available. If the patient is competent, their decision should be respected (however in our case, the patient is incompetent). If the patient is not competent, the decisions have to be made by her relatives and/or representatives, in Luisa's case her husband and daughter. When making decisions in end-of-life situations by proxy, it is important to dedicate adequate time to consultations and interviews with the family or representatives for the decision-making process. This process should be slow, to allow for calm and effective information and communication. Interviews with relatives should explore their possible fears and prejudices, clarifying everything that is necessary for the decision-making to be consistent with the patient's real clinical situation. In Luisa's case, it is important to explain to her husband the difference between euthanasia and palliative sedation, so that her husband understands that he is not consenting to euthanasia, but rather palliative sedation, which only seeks comfort and symptomatic relief.

This case has been studied in accordance with the current legislation in Spain, therefore its resolution may vary in other regulatory frameworks.

For reflection:



- FILM: The Barbarian Invasions.
- ORIGINAL TITLE: Les invasions barbares.
- DIRECTOR: Denys Arcand.
- YEAR: 2003.
- ANALYSIS: Rémy (Rémy Girard) is an old cultured Canadian professor who is dying of terminal cancer. In his country, assisted suicide is legal. Rémy wants to die at home surrounded by his loved ones, so he gathers them together before ending his existence. For this purpose, he resumes the lost relationship with his son and organises an atypical farewell reunion in which, despite him knowing he is going to die soon, he shows himself happy and outgoing. Rémy finally ends his life in his house surrounded by his people, a departure full of love and happiness.

Clinical case

Juan, an 80-year-old patient has chronic lymphatic leukemia and is also the primary caregiver to his wife, who was diagnosed with Parkinson's disease 5 years ago and has developed cognitive impairment. Juan is in the process of declaring his wife legally incapacitated, however this process has not been completed yet. He has decided to register his advance directives (living will) at the Official Registry of his Autonomous Community (regional government). Previously, he had stated his advance directives in front of the notary, but this was before his wife was diagnosed, having named her as his representative. Facing his new situation, Juan asks his primary care doctor if he should update his advance directives and register them again. He also wants to know if his 15-year-old grandson, a resident of his same city, can also register his living will, as he has explained what it is him and he also wants to have a document expressing his last wishes. The doctor asks himself: Should Juan register his Advance Directives (living will) again or is what he previously registered before the notary sufficient? Can a 15-year-old register one's own last will and testament?

Ethical analysis

Juan must contemplate if he wants to designate a new representative to substitute his wife and, in addition, if he wants to change any of the directives of the living will he registered before the notary. His wife will not be able to be his representative as she is not competent to make decisions. Regarding his grandson, the specific norm of the region or country where the case occurs should be consulted.

In Spain, the Advance Directives (AD) are regulated nationally by Law 41/2002, which regulates patient autonomy. Though in addition, specific regulations have been developed by each Autonomous Region, so that each Autonomous Community can prescribe specific requirements that must be met in order to register a person's Advance Directives and regulate how and where to register them. According to article 11 of Law 41/2002, the Advance Directives, also known as a living will or anticipated will, is the document in which a person *"states their will in advance, so that this will may be fulfilled at the time when such person is unable to express their wishes and desires regarding their personal healthcare and treatment,*

or when death occurs, regarding the fate of their body and/or its organs". Regarding how and where to register the AD, each region of country must specify the details in its legislation, in the case it exists.

In any case, decisions that go against the *lex artis* or the legal system cannot be included. Decisions can also be collected regarding the fate of the body or the organs of the patient once they have died. In addition, it is also possible to designate someone for decision making as a representative by substitution.

Possible courses of action

- It is not necessary for Juan to register his Advance Directives until the modifications have been made regarding his request to change his wife's status to legally incapacitated, because he already made his Advance Directives in front of a notary.
- It is necessary for Juan to register his prior Advance Directives again because although they were done in front of a notary they were not officially reregistered at the official registry of his Autonomous Community. Thus, there is no official knowledge that this process was completed and therefore it would not be considered valid.
- It is advisable that Juan modifies his prior Advance Directives if it is his desire to do so, however it is not essential, because in any case, in the context where there is any vital risk he can state his AD (living will) in any format where he can irrefutably express his free and unequivocal will.
- Yes, it is necessary that he modifies his prior Advance Directives due to the fact that in the last few years his clinical circumstances and those of his wife have changed. Therefore, he must go to the Official Registry of his Autonomous Community and establish new AD (living will).
- He can go to his Health Center and register his Advance Directives (legal will) there.
- Regarding the grandson, in Spain a 15 year old cannot register their own Advance Directives, so it would have to be done by the parents of the minor.
- In Spain, a 15 year old person has the right to register their Advance Directives.
- A person who is 15 years old in Spain may or may not register their Advance Directives, depending on the Autonomous Community where they reside.

Recommended courses of action

- Juan must state his last wishes again, and register them with the Official Registry of his Autonomous Community. His wife can no longer represent him due to her lack of competence caused by her Parkinson's disease.
- To facilitate the consultation by the medical team, once the Advance Directives have been written, Juan must provide the document to the Official Registry of his Autonomous Community, or a centre authorized for this purpose, or give it to the new representative so that they may present it for its use when the time comes.
- In relation to his grandson, the regulatory framework of his region or country must be consulted in order to determine if a 15-year-old minor can state their last wishes or living will.
- However, if what is indicated in the Advance Directives (Living Will) by a minor under the age of 18 is clearly against their interest, in accordance with the current Autonomy Law, professionals will be responsible for the protection of the minor's health and life, requesting a judicial authorization if necessary.

Discussion

The purpose of the Advance Directives (Living Will) is to maintain the respect for the patient's autonomy even in those situations where they cannot decide for themselves. The idea is that the patient can make decisions about what they consider most beneficial for them at any given moment and that they can express their values and participate in making decisions about their health even when they have lost the ability to do so. Furthermore, the Advance Directives (Living Will), help and guide family members and relatives in making substitute decisions which, at times, can create conflict. What's more, they help health professionals know who to inform and who to ask for consent in the case that a representative is appointed.

This case has been studied in accordance with the current legislation in Spain, therefore its resolution may vary in other regulatory frameworks.

For reflection:



- FILM: Las Alas de la Vida.
- ORIGINAL TITLE: Las alas de la vida.
- DIRECTOR: Antoni P. Canet.
- YEAR: 2006.
- ANALYSIS: Carlos Cristos is a family doctor who has been diagnosed with multi system atrophy (MSA) at 47 years old. This is an incurable neurodegenerative disease with a poor vital prognosis. Being a doctor, Carlos knows the future that awaits him: a progressive deterioration of his body with increasing dependancy, lack of control of sphincters, loss of body weight, difficulty to walk, move and even to stand up, but without suffering a mental deterioration. Carlos reflrcts on medicine, on illness and its experience, on death and the afterlife. In his living will, he states for his loved ones that if he has a heart failiure, he doesn't want to be reanimated. He prefers to depart from life calmly. A living will performed in front of the screen.

CASES ABOUT THE BEGINNING OF LIFE

Ethical conflicts regarding the beginning of life are to be carefully considered, because manipulating human life in its early stages is always controversial. This happens with issues such as: genetic and embryo manipulation, including their donation; embryo selection for their implantation (which normally implies that the ones that have a genetic pathology be discarded); the various techniques of assisted reproduction, with preimplantation genetic diagnosis; prenatal diagnosis or termination of pregnancy. Though all of these procedures and healthcare actions may be indicated, they are nonetheless difficult to handle. In all of these situations, information and an appropriate clinical relationship are key factors. It must always be borne in mind that the ethical conflicts will have to be solve within the current legal framework.

- In the first case selected, a couple asks for a genetic prenatal diagnosis in order to discard the presence of risk factors for breast cancer in the foetus.
- The second case is about assisted reproduction (in vitro fertilisation) and donor selection. In these procedures, the future parents can request to choose the donor, carry out a genetic selection among pre-embryos or choose, for example, the sex of the future child.
- The last case is one about child adoption. The fact of adoption is revealed during a genetic diagnosis consultation, which leads to various problems difficult to solve regarding the management of information, data confidentiality, and the management of healthcare resources.



Joaquín Sorolla, Medical Research, or Doctor Simarro in his Laboratory.
How painting has witnessed medical breakthroughs.

Clinical case

Manuela, a 38 year old woman with a history of breast cancer, is in her 16th week of pregnancy. Various forms of breast cancer exist in her family. She and her husband are monitoring her pregnancy through a public hospital and if the sex of the fetus is female, they would like to have a prenatal genetic screening test to rule out the possibility that it has the genetic mutations BRCA1 and BRCA2. If the fetus has these mutations, they would like to terminate the pregnancy. The hospital's gynaecologist took this case to the Ethics Committee with the following question: Should we perform this prenatal genetic screening test at our hospital?

Ethical analysis

The primary values in conflict in this case are: on the one hand to respect the parents wishes to perform the prenatal genetic testing (PGT) and on the other hand, the adequate distribution of financial resources, because PGT is very expensive, and also the protection of a life in utero. In order to perform the PGT it would be necessary to practice an amniocentesis, which is not without risks and as a result can lead to complications such as an abortion.

In this case, the first thing to clarify is that being a carrier of BRCA1 and BRCA2 does not meet the criteria for a legal voluntary termination of pregnancy (VTP). Being a carrier of BRCA1 and BRCA2 is a risk factor for having an adult disease (gynaecological cancer), however it is not a disease. The mutations of BRCA1 and BRCA2 do not necessarily imply that their daughter will develop this disease, rather, that she is at risk to be predisposed to the appearance of some cancerous pathologies, mainly breast and ovarian, but not all patients with the mutation will suffer from breast and ovarian cancer. It would not be the same, if for example, the fetus had Thalassaemia Major, or Trisomy 21.

Possible courses of action

- Not perform the prenatal genetic screening test; as being a carrier of BRCA1 and BRCA2, does not meet the criteria to voluntarily terminate the pregnancy (VTP).
- Study if the mother meets the risk criteria in order to carry out a genetic screening test for mutations BRCA1 and BRCA2. If so, perform the genetic screening test on the mother.
- If the mother is a carrier of the mutation, perform the prenatal genetic screening on the fetus. If she is not a carrier, then refuse to perform the test on the fetus.
- Inform the patient and her husband about the implications of the mutations BRCA1 and BRCA2 in detail, then verify that they have understood the information.
- If the fetus is a carrier of the mutation, not carry out the termination of the pregnancy.
- If the fetus is a carrier of the mutation, perform the abortion.

Recommended courses of action

- Inform the patient and her husband in detail about the implications of a mutation in BRCA1 and BRCA2. Inform them of the criteria for a VTP and verify that they have understood the information.
- The prenatal Genetic screening test cannot be performed: being a carrier of BRCA1 and BRCA2 does not meet the legal criteria to voluntarily terminate a pregnancy (VTP).
- Furthermore, with the current regulations in Spain it wouldn't be possible to have an abortion as her pregnancy has passed the legal limit for voluntary abortion (up to 14 weeks) and the presence of a mutation that increases the risk of an illness is not justification to voluntarily terminate a pregnancy due to medical reasons.
- If the mother meets the risk criteria, the genetic screening test would be performed on her, and if she is a carrier, the recommendation would be to perform the genetic screening on her daughter after her birth.

Discussion

In the case being studied, a VTP could not be authorized for being a carrier of BRCA1 and BRCA2. Putting a fetus at risk without any real consequences (a VTP could not be performed) would not be acceptable in this case, and performing an amniocentesis would not be indicated. Here, a question arises: What if it were in the 10th week of pregnancy? In the public health system the PGT would not be authorized, since being a carrier of BRCA1 and BRCA2 does not meet the criteria for a VTP. In a private center, perhaps the test could be performed (first it would be performed on the mother) and then depending on the results, the parents could choose to have a VTP, since they would be within the legal limit (less than 14 weeks).

Therefore in the case that is suggested above, it is essential that the patient and her husband first have all the necessary information regarding the test and about the criteria for a VTP. It is also important that they know and understand what procedures are necessary to perform the PGT, the possible complications, and the usefulness of the results at the present time.

Regarding whether the test should be carried out on the mother to see if she is a carrier of the mutation BRCA1 and BRCA2, it can be done, however, in this case there would be no subsequent consequences to the fetus since, regardless the results, neither a PGT nor a VTP could be performed. If the mother meets the criteria for the risk, then she could have the genetic testing done, and if the result of that test is positive, then after the birth of her daughter the test may be performed on the baby following the current guidelines. In the event that the patient's daughter were a carrier of the mutation, early screening protocols should be applied.

This case has been studied in accordance with the current legislation in Spain, therefore its resolution may vary in other regulatory frameworks.

For reflection:



- FILM: *My Sister's Keeper*.
- DIRECTOR: Nick Cassavetes.
- YEAR: 2009.
- ANALYSIS: The parents of Anne Fitzgerald (Abigail Breslin) have had her to be able to treat their other daughter Kate (Sofia Vassilieva), who suffers from leukemia since she was two years old. Anne was conceived by in vitro fertilisation in order to serve as a “medicine baby” to save her sister’s life. Her parents have decided what tissues they gradually extracted from her to treat Kate. When at 16 years old, Kate needs a kidney in order to stay alive, Anne, who is 11, refuses. She is exhausted of serving as a “tool” for her sister. Anne refuses to be submitted to more surgical interventions, so she sues her parents to win the legal authority to choose about her health and, consequently, that of her sister’s.

Clinical case

Pedro, a 35-year-old, white Spanish man, and Celestine, a 30-year-old black woman, originally from Equatorial Guinea, visit a fertility clinic. After trying to conceive for the last two years they haven't managed that Celestine gets pregnant. After examination, the clinic finds that Pedro has mild gynecomastia and almost no hair. His genitalia are small, he has severe oligoasthenoteratozoospermia and a 47 XXY karyotype (Klinefelter syndrome). The couple is in need of artificial insemination with donor sperm.

At the consultation, they are informed that the donor must remain anonymous and that the donor will be screened for genetic and infectious diseases. A donor will be sought with genotypic compatibility with the woman (Rh and ABO blood group) and with phenotypic characteristics (among those available in the sperm bank) similar to those of the woman: ethnic group, skin color, height, weight, hair color and texture, and eye color.

Celestine disagrees with this last point. Her husband is white and she would like the donor to reflect her husband's characteristics instead of hers. She wants to preserve the privacy of the fact that the child is the result of a donation and also, she feels that, based on her experience, socially her child's chances will be better if he/she is not black. Celestine requests that the sperm donor be Caucasian. The gynaecologist is hesitant to grant Celestine's request.

Ethical analysis

Assisted reproduction techniques and the handling of gametes and embryos produce multiple ethical and legal conflicts. In this case, the mother wants to choose certain phenotypic characteristics of the donor. She believes that if the donor is white, they will be able to maintain privacy regarding the type of fertilization performed. She also believes it will be more beneficial for their future child if the donor is white like the father as he/she will find it easier to socially integrate and have more opportunities than if he/she is black. However, the mother's wishes violate Article 6.5 of Law 14/2006, of May 26, 2006, on assisted human reproduction techniques. Article 6.5 of this Law states the following: *"In the application*

of assisted reproduction techniques, the choice of the sperm donor can only be made by the medical team applying the technique, which must preserve the conditions of anonymity of the donor. In no case may the donor be personally selected at the request of the recipient. In any case, the corresponding medical team must try to ensure the greatest possible phenotypic and immunological similarity from the available samples with the recipient woman”.

Consequently, there is an ethical conflict between respecting the autonomy and desire for privacy (regarding the method of fertilization) of the future mother, who wants to choose the color of her child’s skin, and the fairness and equality of the service. All women who have access to this service (sperm donation) have a common rule: that the donor should look as much like the mother as possible. Therefore, if a woman was allowed to choose what a donor looks like phenotypically, she would be receiving special privileges with respect to others.

Possible courses of action

- Grant the couple’s request. Put them in direct contact with the sperm bank so that they can choose who they consider the most suitable donor.
- Lie when requesting sperm from the bank and ask for a white donor (saying that the mother is white).
- Explain to the mother that currently in Spain, opportunities are similar for people regardless of race and ethnicity.
- Set up a consultation with both parties and explain the Spanish regulations in detail and give them an opportunity to reflect on the real options within the law.
- Tell the couple that the law must be followed: the sperm must be from a donor as similar to the mother as possible.
- Suggest to the couple that they seek fertilization in a country where the legal requirements are different and allow the recipients to choose the donor.
- Propose other alternatives, such as adoption or foster care.
- Consult the National Commission on Assisted Human Reproduction, under the Ministry of Health, to see if this case could constitute an exception to the current rule.
- Bring the case to court and request judicial authorization for the use of semen from a Caucasian donor.

Recommended courses of action

- In this case and with the current legislative framework, the only possible option is for the medical team to choose a donor with the greatest possible phenotypic similarity to the woman. If not, the couple (the woman) will have to forego assisted reproduction, and look for other alternatives outside Spain or try to have an exception made for her case.
- In this scenario, it would be beneficial to give the couple time to reflect on their alternatives. It is also advisable to have a consultation with them in which the Spanish regulations can be explained further and they are given an opportunity to reconsider.
- If still the woman persists in her desire for a Caucasian donor sperm, viable alternatives should be explained (if possible with the help of a social worker): donation in another country with a different legal framework or adoption.
- An interesting option would be to consult the National Commission on Assisted Human Reproduction to see if they feel that this case constitutes an exception to the current rule.
- If, after all this, the woman does not obtain authorization and continues with her demands (assisted human reproduction in Spain and from a Caucasian donor), she could consider the option that, given her circumstances, the donation of white donor sperm be judicially authorized.

Discussion

A case is presented in which a black woman requests a white donor, in violation of the law. There is an ethical conflict (privacy and autonomy VS equitability), but also a legal conflict because the mother's wishes are contrary to the norm. If the ethically preferable course of action (in this case accepting a white donor) is contrary to the law, it must be rejected and an alternative must be sought. Therefore, no Health Care Ethics Committee could recommend the donation of a Caucasian donor, because it is not prudent to make an ethical recommendation contrary to the law.

If in the case presented, the woman insists in her idea even after a thorough explanation of the legal framework and the available options, then the case should be brought to the National Commission on Assisted Human Reproduction, and see if it issues a recommendation that differs with the assumptions of the law.

In any case, the judicialization of the case should be avoided, since this is always an extreme course of action and should only be resorted to in truly exceptional situations and when fundamental values are at risk.

For reflection:



- FILM: Gattaca.
- DIRECTOR: Andrew Niccol.
- YEAR: 1997.
- ANALYSIS: Vincent (Ethan Hawke) was born through natural conception but lives in a world dominated by genetic manipulation. At birth, children are subjected to a genetic test to foresee future illnesses.. Vincent is predicted cardiac issues and a premature death at 30 years old. He is a “non valid” (the valid ones are those who have perfect genes). His parents have a second child, Anton (William Lee Scott), who is genetically improved to ensure he has a better future. Vincent buys samples of different tissues from Jerome Eugene Morrow (Jude Law), a genetically “valid” young man who is paralytic since he had an accident. If he manages to make the tissues seem his own (his genes), Vincent will be able to join the Gattaca corporation and fulfil his dreams.

SHOULD INFORMATION REGARDING THE ADOPTION OF THE PATIENT BE WITHHELD?

Clinical case

Isabel, age 52, has been diagnosed with breast cancer. Faced with the possibility of a genetic origin (her aunt and mother both died of breast cancer), a genetic study for BRCA1 and BRCA2 is performed to rule out hereditary cancer. The results turn out positive. Therefore, her closest relatives on her maternal side are referred to a genetic counseling consultation: her sister and her daughters Andrea and Elena. Dr. Jiménez has an appointment with 22 year old Elena for consultation the following day. She plans to suggest a very close follow-up with imaging tests (MRI, mammography, echo), in order to, based on the findings, consider whether it is necessary to carry out the genetic test, which is expensive. Isabel, without a scheduled appointment, shows up at the genetic counseling office to speak with the doctor. She informs Dr. Jiménez that one of her daughters, Elena, is not her biological daughter. She was adopted and, however, Elena is not aware of this. Isabel, tells Dr. Jiménez that she doesn't want Elena to know that she is adopted. She suggests that she tell Elena that "she doesn't need to have the tests done" because "there is no risk", or that she goes ahead with the tests in order to avoid telling her that in reality, she is not her biological daughter. Dr. Jiménez is concerned about withholding this information from Elena, in addition to having to carry out unnecessary tests and a follow-up, since Elena is not at an elevated risk of suffering from hereditary breast cancer. Should Dr. Jiménez conceal Elena's adoption information from her? Should she still request for the tests she planned to be done?

Ethical analysis

When assessing which values are in conflict in this case, we find that they are, on the one hand, the veracity of the information, the protection of health (non-indicated tests would be carried out, which are not innocuous and thinking that she is at risk of breast cancer may create anxiety to Elena) and the proper use of healthcare resources (unnecessary tests should not be carried out). On the other hand, we find the respect for confidentiality and professional secrecy.

Regarding the values at stake, we must clarify that:

- One of the pillars of clinical relationship is confidentiality; which is an ethical requirement and a legal duty. Healthcare providers have committed to professional secrecy, but this commitment is not absolute and can be broken in the event of harm to third parties.
- There is a risk of harm to Elena because the tests are not indicated. Not knowing the identity of her biological parents, the real risk Elena is exposed to is unknown, however, the cases in which parenthood is unknown are not treated as high risk cases but as conventional ones. Medical procedures are not free of risk and should only be performed when they are indicated, as otherwise the patient's best interest is not being sought and, in addition, unnecessary tests may cause avoidable harm. Carrying out the tests is, therefore, maleficent due to both the exposure to radiation and because misinformation (and the consequent experience of risk) can cause moral damage.
- Conducting non-indicated tests is a misuse of resources and an unnecessary expense. The use of healthcare resources should be rational and responsible.

Possible courses of action

- Go along with the plan to not tell Elena anything, as her mother suggests: carry out the image tests, the follow up, and hide from her that she is adopted. Additionally, it is not actually known if Elena is at an elevated risk for hereditary breast cancer as it is unknown who her parents are.
- Carry out the genetic test on Elena, which is expensive and would not be indicated as she could no longer be classified as a patient at high risk for hereditary breast cancer.
- Find out who Elena's biological parents are and see if there have been cases of breast cancer in their family, and then act accordingly after the findings.
- Call Elena to cancel her appointment and inform her that she doesn't need to come to the consultation because she isn't at risk, but without explaining her why.
- Inform Elena that she is adopted, despite her mother's wishes, because this will avoid unnecessary tests and follow-ups which could be potentially harmful.

- Inform Isabel that no unnecessary tests should be conducted on Elena, as they are not indicated and, if performed, they would imply a misuse of health resources.

Recommended courses of action

- Inform Isabel that unnecessary tests should not be carried out on Elena as they are not indicated and, in addition, doing so would represent a misuse of healthcare resources and cause unnecessary moral damage to Elena.
- Isabel must also be informed about the ethical and legal responsibility of the doctor to be truthful at all times and not cause intentional harm. Likewise, that the doctor also has a legal and ethical obligation to protect confidentiality and to maintain professional secrecy, but that this obligation can be broken in the event of damage to third parties.
- Therefore, Isabel must clearly understand that doctors cannot lie or cause avoidable damage.
- Isabel must be given time and the opportunity to speak with her daughter to explain that she is adopted, thus delaying the appointment with Elena. Help can be offered to Isabel to assist her in giving this information, including informing her that she may join the appointment with her daughter to inform her of the cancellation of the tests and the reason why.
- If after all this, Isabel is still not convinced, Dr. Jiménez will have to tell Elena that she is not at risk for hereditary breast cancer. Dr. Jiménez cannot subject Elena to unnecessary tests and have her falsely believe she is at risk. Should this situation occur, it would be highly advisable to consult with the legal team at the center.
- In no case would Dr. Jiménez unilaterally inform Elena about her adoption.

Discussion

For Isabel to understand the ethical and legal conflicts at stake, it is important to communicate with her efficiently and effectively optimize the information. We must explain that it is not acceptable to perform procedures that are not indicated, as they may have secondary effects because they can cause avoidable harm,

without also forgetting the moral damage of having Elena falsely believe that she is at risk. In order to convince Isabel that she should change her mind, she must be given her time. The doctor can also offer to help inform Elena of the situation, even personally accompanying Isabel in the process of informing Elena about her true origin, so that she does not feel abandoned by Dr. Jiménez.

If after all this, Isabel is still not convinced, Dr. Jiménez will have to tell Elena that she is not at risk for hereditary breast cancer, as she cannot subject Elena to unnecessary tests and have her falsely believe she is at risk. However, without Isabel's permission, she cannot reveal the information regarding the adoption. If this situation occurs, it would be highly advisable to consult with the legal advice team at the center, in order to act, at all times, in accordance with the legal norm regarding adoption.

For reflection:



- FILM: The Kids are All Right.
- DIRECTOR: Lisa Cholodenko.
- YEAR: 2010.
- ANALYSIS: A lesbian couple (Annette Benning y Julianne Moore) have two children through artificial insemination from a sperm bank. When their children (Mia Wasikowska y Josh Hutcherson) are teenagers, they cannot stop wondering who their biological father is. When the eldest sibling turns 18, in accordance with the California law, he requests information about his biological father. The father turns out to be Paul (Mark Ruffalo), a very peculiar man. The encounter of Paul with his children will change their lives.



Luis Jiménez de Aranda, Hospital Ward during the Round of the Chief Physician (The Doctor's Visit).

Everyday life in a hospital and first reference to a female medicine student.

CASES REGARDING PROFESSIONALISM

In addition to the ethical conflicts derived from their healthcare activity, healthcare professionals can encounter problems related to their professional obligations. These cases have undeniable ethical connotations which originate doubts about the limits of professional responsibility.

- In the first of these cases, a conflict with the objection of conscience is posed, which is one of the situations that causes most doubts for healthcare professionals. It is important to know when the objection of conscience can be exercised and what its limits are. The aim is to clarify how the objecting professional should act.
- Conflicts of interest can compromise professionalism. An example of this can be the payment of incentives by the pharmaceutical industry. A case is posed in which a pharmaceutical company seeks to encourage the participation of a doctor in a research project by paying their attendance to a course.
- The third case is about the professional relationship among colleagues. What must be done if the professional performance of a colleague poses a threat to the patients or even to other colleagues or the institution? These conflicts are difficult to manage because reporting the situation can harm the colleague and deteriorate the work environment. The professional must be protected if possible but also the patients and the rest of the colleagues.
- The coronavirus pandemic has entailed a challenge for healthcare professionals. It overwhelmed the health centres, which were lacking the resources necessary to protect both patients and professionals. A case is presented in which the healthcare professionals faced problems due to a lack of resources.
- In its early stages, the coronavirus pandemic caused a great deal of therapeutical uncertainty and high doses of anxiety in healthcare professionals. Many treatments were tried out with the hope they would be effective (and without knowing their real effects on the illness), based on their pharmacodynamic properties and on the experience by other healthcare professionals, but lacking previous scientific studies. A case that occurred during those first stages of the pandemic is presented in which the professionals had to decide whether to focus on research or to treat the patients “blindly”.

Clinical case

Ana is a 39-year-old married woman with three children, aged 14, 11 and 4. Since the birth of her third child she has been using oral contraceptives because neither she nor her husband wish to have more children. After having a urinary tract infection, she was prescribed an antibiotic. However, she was not warned of the possibility that her oral contraceptive might lose efficacy due to the antibiotic, thus resulting in Ana becoming pregnant.

Upon discovering the news, they decide to consult their family physician, Dr. Jiménez, the only doctor in their local health center as they reside in a small town. During her consultation Ana asks for the necessary information in order to start the process of terminating her pregnancy, as she and her husband have decided they would like to have an abortion. The doctor then alleges a conflict of conscience and refuses to give them the necessary information. Does the Doctor have a right to object? How should he/she act in this situation?

Ethical analysis

In the case presented, the principal values in conflict are, on the one hand, the right of the patient to receive information and healthcare, together with the consideration of her freedom of choice (within good clinical practice and the healthcare service portfolio, as in this case), and on the other hand, the observance of the personal convictions of the healthcare provider.

In Spain, conscientious objection has been defined, according to the Constitutional Court (CC), as “*the right to be exempt from fulfilling one’s legal or constitutional duties, due to them being in conflict with one’s own convictions*” (STC 161/1987, 27th of October). Since 1985 the CC has recognized that Doctors have the right to conscientiously object, which extends to the health field in general, based on the fundamental right of freedom of opinion contained in article 16.1 of the Spanish Constitution (STC 53/1985). Subsequently, this right has been specifically regulated in article 19.2 of law 2/2010 of sexual and reproductive health and the voluntary termination of a pregnancy (VTP) for Doctors generically, in chapter VI of the Code of Ethics (CD) of 2011: “*The recognition of con-*

scientious objection for a doctor is essential in guaranteeing the liberty and independence of their professional practice. Neither a collective or institutional conscientious objection is admissible”.

Possible courses of action

- The Doctor has no right to object: the Doctor is obligated to inform the patient, and therefore must do so. If the Doctor objects, then the head of the center must report the incident to the College of Physicians and assess whether to present the case to the courts.
- Not inform the patient and not offer them an alternative solution.
- Inform the College of Physicians of one's desire to be a conscientious objector and the cases which one would like to object to.
- Communicate to the head of the health center in advance regarding the cases to which one would like to object.
- Record the actions (the possible objection and their reasons) in the patient's medical history file.
- Refer the case, providing the proper background, to another doctor within the center who can inform the patient about the process of voluntarily terminating a pregnancy.
- Not inform the health center or the Board of Physicians of one's objections and refer the patient to another doctor at a health center nearby.

Recommended courses of action

- Communicate in advance to the head of the health center the cases in which one would like to conscientiously object, so that care can be organized for those cases.
- Communicate to the College of Physicians one's desire to be a conscientious objector and which situations one would like to object to.
- Inform the patient that the Doctor is an objector and refer the case on to a colleague at the health center (which has been previously arranged) without Dr. Jiménez passing judgement or giving an opinion on the patient's decision.

- Refer the case, correctly explained, to the doctor that the Health Department has provided for these cases, and have this doctor provide the information to the patient regarding the voluntary termination of pregnancy (given that Dr. Jiménez had previously communicated her status of conscientious objector, the Health Department has to plan who will replace her in those situations).
- It is not necessary to explain the doctor's status as a conscientious objector in the patient's clinical history, since this is private information of the doctor and not relevant to the patient's care.

Discussion

The current Spanish regulatory framework establishes that conscientious objection must comply with the following characteristics in order to ensure that both the right of the doctor to object and the patient's right to healthcare are protected:

- The patient's right to care must remain intact and therefore a professional replacement should be found, one who guarantees the patient's care, while respecting their autonomy and their decisions.
- In order to guarantee the previous point, the person who is objecting must previously communicate in writing "to the person in charge of guaranteeing the service and optionally the College of Physicians regarding their condition as a conscientious objector" (CE) the situations in which they will exercise their right to conscientiously object.
- The objector cannot refuse treatment to groups or individuals based on religious or ideological differences, nor a difference of beliefs, except in specific clinical situations where the professional's conscience is deeply violated.
- Objection is a personal action. Collective objections are not valid.
- Opportunistic situations will not be acceptable, i.e. cases in which a doctor objects in one health center but not in another. That is, there must be consistency regarding conscientious objection.
- An objection cannot cause damage nor can it benefit the doctor objecting. Therefore, the professional must compensate the objection with another activity and cannot be discriminated against for their objection.
- Finally, we must not forget that in critical situations with a risk of life, if there is no other professional, the doctor who conscientiously objects must attend to the patient, otherwise they would be committing an abandonment of the patient.

In accordance with the current Spanish norm (Law 2/2010), the healthcare personnel who may object to the VTP are those who are directly involved in carrying out the procedure. There is a debate about whether family doctors and the staff who have to provide information about VTP (for example, administrative staff and nurses) are “directly involved” and also whether if giving healthcare information is included in the cases of conscientious objection. In Spain, the judicial sentences in this regard have gone both ways, some supporting the doctor conscientiously objecting and others against the right of the doctor to conscientiously object to giving information. The CC has not yet ruled on the matter. Currently, according to the Medical Code of Ethics, in certain areas doctors are allowed to conscientiously object to giving information, provided that information from another professional is guaranteed.

The proposed courses of action and the resolution of the case could vary depending on the laws and regulations of each country about conscientious objection. Generally, it is considered a right of the professionals, though within certain limitations. For this reason, the way of exercising the objection must be found without causing patient abandonment and without harming their healthcare rights.

This case has been studied according to the current legal framework in Spain. Consequently, its resolution can vary in other regulatory frameworks.

For reflection:



- FILM: The Cider House Rules.
- DIRECTOR: Lasse Hallstrom.
- YEAR: 1999.
- ANALYSIS: Dr. Wilbur Larch (Michael Caine) works at the St. Cloud orphanage. Homer Wells (Tobey Maguire) is born and raised at St. Cloud, learning medicine from Dr. Larch. Determined to enable Homer to fulfill his medical vocation, Dr. Larch forges some documents and produces a certificate which will allow him to practice as a physician. As the years go by, Homer's responsibility in the sanatorium grows and he comes to disagree with Dr. Larch's methods, particularly regarding abortion. In an era in which it is still illegal, Dr. Larch provides the service justifying it with its utility in tragic circumstances. His disciple doesn't understand and invokes mother's responsibility.

IF THE PHARMACEUTICAL INDUSTRY PAYS A COURSE FOR ME, SHOULD I ACCEPT?

Clinical case

Manuel, who is doing a residency in pulmonology, asks a pharmaceutical sales representative if they can finance a pulmonology course for him at Massachusetts General Hospital. The drug rep informs Manuel that they cannot pay for his course registration or the trip. However, he mentions that they could assist him if he participates in a study sponsored by the pharmaceutical company. It's an observational study, in which he has to fill out 15 surveys regarding the progress of 15 patients who would be put on an inhaler marketed by the pharmaceutical sales representative. In addition, he would receive 150 euros for each patient included in the study. The sales representative provides the study protocol, approved by the Research Ethics Committee. It is a multicenter, competitive study (that will end when the sample size has been reached), in which 150 cases are to be collected.

After speaking with the pharmaceutical sales representative, Manuel isn't sure whether he should participate in the study. On the one hand, he thinks: "after all, it is a good inhaler and, if it has been recommended, I have no objection to using it". Yet, on the other hand, he wonders whether his prescription is being skewed because in order to be able to attend the course he would have to take part in the study.

Should Manuel participate in the study as a means to attend the course?

Ethical analysis

A physician must always prioritize what is in the best interest of the patient over any other personal interest. Therefore, they must provide the most beneficial prescription for each individual patient. Medical prescriptions can be skewed by certain personal interests (money, prestige, etc.). However, this should be secondary as they can undermine the quality of the healthcare provided. The problem is that a physician may not prescribe the most appropriate drug for a patient due to the influence of his/her secondary interest, in the case presented here, the influence of the pharmaceutical company on the resident by financing a course.

These situations present a conflict of interest between the ability of the physician to prescribe freely seeking the patient's best interest and another interest or personal benefit (sometimes a material interest), obtained in exchange for the prescription. In medicine, conflicts of interest can be aggravated by the lack of perception of the professionals themselves. Physicians are often unaware of how incentives (e.g., from the pharmaceutical industry) can influence or modify their actions.

When participating in studies or research projects, benefits or incentives cannot be in the form of payment for training, enrollment in courses, gifts, or meals. In research, any payment to the professional for their work (patient recruitment, time dedicated to the study, etc.) must be monetary and under contract in accordance with the rules and standards regulated by law.

As previously stated, in this case, the physician asks the pharmaceutical sales representative for a course to be financed by them. The sales rep states that they are unable to pay for the course and instead offers the physician to participate in a study for a treatment that they are promoting and that will be prescribed. Participation in the study, in any case, must follow all the guidelines and ethical norms of research: authorization by a Research Ethics Committee, signing of a contract, etc. However, Manuel fears losing his independence and freedom to prescribe, as he might be encouraged to prescribe the inhaler marketed by the sales representative in order to complete the study (and be able to finance the course).

Possible courses of action

- Refuse any contact with sales representatives and representatives of the pharmaceutical industry.
- Refuse to participate in the study and therefore forgo the reception of money for prescribing the inhaler to patients.
- Ask the sales representative for all information regarding the study in order to analyze its design and decide whether to participate in the study accordingly.
- Explain to the representative that if they participate in the study, it is for scientific reasons only and not to attend the course.
- Assess the prescription of the inhaler, its price, and possible alternatives.
- Accept the invitation to participate in the study, sign the corresponding contract, and prescribe the inhaler to all potential candidates.

Recommended courses of action

- First of all, the physician must assess the prescription of the inhaler, its price, and all possible alternatives. The inhaler should only be prescribed in cases where it is appropriate, meaning, if it will be of value to the patient and if there are no better alternatives. Furthermore, the prescription of the inhaler should not result in any excessive overcharges to the patient or the health system, if possible.
- Ask the sales representative for all the information related to the study. Manuel should collect as much information as possible to assess the design and suitability of the study. Participation in the study should be based on scientific criteria, not personal interest.
- Explain to the sales representative that if he chooses to participate in the study, it's not to attend the course, but for scientific reasons. Manuel cannot sign up for the study just to attend the course. Spanish regulations forbid planning, performing or financing observational studies as the one referred to, which are aimed to promote the prescription of drugs that are the object of study.
- If Manuel decides to participate in the study, he must obtain approval from the person in charge of the center or service where he works, and such approval will be certified through a mandatory contract signed with the study sponsor. In Spain, only when the study sponsor belongs to the health center or service where the study is being conducted, will a contract not be necessary, the express consent by the person in charge being sufficient. At this point, certainly, the regulations of each country must be followed.
- Whatever decision the professional makes must be transparent and communicated in any such publications related to the study. It must be based on the Declaration of Helsinki and the applicable regulations, and also explained to the patients participating in the study when obtaining informed consent.

Discussion

- Physicians sometimes face situations in which their primary role as professionals comes into conflict with other (secondary) interests, resulting in a conflict of interest.

- The physician must prevent their personal (secondary) interests from taking precedence over their primary purpose, which is the pursuit of the patient's well-being. He/she should always seek what is in the best interest of the patient.
- When physicians come into contact with the pharmaceutical industry, these conflicts of interest may arise. Moreover, they may not be aware that their prescription is influenced by external agents who offer them training or material benefits (gifts, meals, etc.).
- To prevent and minimize the risk of conflicts of interest it is essential first to identify the conflict. This is why it's very important that physicians are adequately trained and familiarised with what constitutes a conflict of interest. Physicians need to undergo specific training regarding conflict of interest awareness, which should include both ethical and legal aspects.
- When participating in research studies promoted by the pharmaceutical industry, a physician must not accept any compensation other than monetary payment for his or her time commitment and for the additional expenses incurred in carrying out the study.
- The possible conflicts of interest should be disclosed and reported both to the scientific community (articles, conferences, congresses, etc.) and to the patients who may participate.
- It is necessary that physicians know the specific legislation in force in the country where they carry out their medical practice, in order to avoid conflicts of interest and actions contrary to the norm that can violate professional ethics and be a cause of professional liability.

This case has been studied in accordance with the Spanish current legislation, therefore its resolution can vary in other regulatory frameworks.

For reflection:



- FILM: Side Effects.
- DIRECTOR: Steven Soderbergh.
- YEAR: 2013.
- ANALYSIS: Emily Taylor (Rooney Mara) suffers from a severe depression, including suicide attempts. Psychiatrist Dr. Jonathan Banks (Jude Law) prescribes for her a new experimental drug called Ablixa. The side effects of the drug make Emily kill her husband while she is in a state of “sleep walking”. Emily is admitted in a psychiatric hospital and Dr. Banks breaks down. The case seems to be closed, but Dr. Banks cannot accept the idea of bearing all the responsibility and continues to investigate in order to clear his name. He will discover how the pharmaceutical industry and the conflicts of interest it causes can lead to ruining a life.

Clinical case

Julia has been working in the cardiology service for years. Her colleagues have recently observed that she is often inattentive when treating her patients, and she makes inappropriate comments in the clinical records, including improper personal issues. During guard duty, her colleagues frequently encounter problems with her patients because her clinical management is inadequate and both the patients and their relatives complain about the care she provides. The team has tried to address these issues with Julia. However, she sees no problem in her work and always justifies her actions, with different arguments each time. Her colleagues have doubts about how to proceed, whether they should bring this to the attention of the head of the department or the hospital management, as the consequences to Julia could be severe, for example, the loss of her license.

Pablo, a colleague of Julia in cardiology, has had to change prescriptions written by Julia more than once. Julia's way of dealing with patients is inappropriate, but Pablo is particularly concerned about the health consequences for patients due to Julia's behavior. Pablo is unsure of what to do: is he acting correctly by protecting Julia? Should he report the situation for the sake of the patients?

Ethical Analysis

A physician's priority should always be the health and well-being of patients. Therefore, when faced with conflictive situations regarding colleagues, any solution that is made should be in their best interest. Even if they are not directly in charge of a patient's care, the physician has a duty to protect them if they learn that such care is being damaged, as will happen if a colleague is mistreating patients. In addition to Julia's inappropriate behavior with patients, the clinical relationship and the trust of the patients and their relatives in the healthcare team as a whole are deteriorating. It is even possible that the patients' autonomy is being affected, because they may not be able to make well-informed decisions if the communication with them is inadequate.

On the other hand, Julia has been Pablo's colleague for years. They've had a good professional and even personal relationship. Their families know each other

and, until a year ago, Julia was very respected at the hospital both as a cardiologist and as a human being. Pablo fears that, if he reports the situation, Julia will be fired, which will lead to her have a personal crisis where he will be blamed for ruining her life. He is also afraid that, in retaliation, Julia will report him, resulting in negative consequences for himself.

In this conflictive situation, the solution may harm Julia, and no one wants to harm a colleague. We are therefore faced with a conflict between, on one hand, protecting the patients' health and well-being and, on the other hand, the respect for the prestige and professional career of a colleague. We must not forget another important factor at stake: the friendship that binds Pablo and Julia. In situations where there is a risk to the health of patients, every step must be taken to resolve conflicts as quickly and smoothly as possible. It's important to analyze the situation carefully and to be creative when coming up with the best resolution. Ideally, both the patients' and Julia's trust and wellbeing should be protected and ensured. If it is not imperative, we should try not to harm Julia. In short, we should seek the balance of an action that ensures the protection of patients and, as far as possible, doesn't harm Julia or her reputation.

Possible courses of action

- File a complaint in court about Julia's negligence.
- Warn patients that Julia is an unfit doctor and that she may put their health at risk.
- Inform the hospital management about these ongoing issues.
- Speak with the head of the department so that they can make the decision.
- Talk to Julia: ask her if she has a problem, explain the seriousness of the situation, and help her as much as possible to correct her attitude.
- Talk to the other colleagues on the cardiology team to try and figure out a solution together.
- Not report the case and supervise Julia's actions to ensure patients are not harmed by Julia's possible loss of professional skills.
- Not inform anyone about the case and continue to let Julia do her job. After all, it's not the responsibility of a doctor to investigate and/or report colleagues.
- Make an anonymous complaint to the hospital management and the head of the department, so that Julia doesn't know that Pablo is the one who reported her.

Recommended courses of action

- First and foremost, speak with Julia. Pablo should speak directly with her, explain the seriousness of the situation and ask why this has been happening, expressing his concern to know if there is a reason that can justify her behavior. Thus, Pablo will be able to assess whether Julia is fully cognizant of the situation and if there is any cause that could be addressed to help her correct these issues.
- It would also be good to incorporate the rest of the colleagues in the cardiology team to try to find a solution together. On one hand, that way Pablo will feel supported and he will not bear the responsibility of the decision alone if it is necessary to report Julia. Secondly, together they will surely be able to analyze and solve the problem better. This task of analyzing the problem and finding a solution should be coordinated by the head of the department, who is ultimately responsible for the proper functioning of the cardiology department as a whole, not Pablo. The head of department should be made aware of the problem, and be in charge of analyzing and organizing the conversations on how to solve it.
- If it is decided among the team that there is indeed a lack of professionalism by Julia, her work should be supervised until a solution is found.
- This whole process should be carried out as delicately as possible, without singling out anyone (for example, Pablo) as the source of the inquiries. The head of the department should make it clear to Julia that the problem has been detected by the whole team and that together they are seeking the best solution.
- In order to protect her privacy, Julia's situation should not be discussed with the patients. It is necessary to maintain the confidence and trust in the care team, so Julia should not be criticized in front of patients or family members.
- If the cause of the problem is easily addressed and is corrected after this initial intervention, then a follow-up should be done. The cardiology team should monitor Julia and make sure that her work is being performed optimally.
- If this is not the case, meaning a readily addressable cause is not detected, and the health care of patients is therefore at risk, then the problem should be reported to the hospital management.

Discussion

- Conflicts with colleagues are common in the workplace. When these conflicts negatively impact patients, we should seek solutions that protect the health of our patients while also trying not to harm our colleague.
- In situations such as these, communication with the affected person is essential. We should talk to Julia, explain that we are looking out for her and her patients' best interests. She should be asked if there is any reason why her work performance has been compromised. It's important that Julia becomes aware of the situation and its seriousness, trying to avoid her feeling "attacked" by her colleagues.
- If this step is ineffective, then an appropriate short-term solution must be sought because the health of patients may be at risk. In the meantime, Julia's performance should be monitored to protect the patients while a solution is found.
- As all these actions may have negative consequences on Julia's employment and professional status, transparency is essential. Julia must be informed of all actions that are going to be carried out. It would be ideal to preserve her trust, however we must not forget that protecting the health of patients is our number one priority.
- In extreme cases, if unlawful actions are taking place, it may be necessary to report the case to the proper legal authorities.

For reflection:



- FILM: Extreme Measures.
- DIRECTOR: Michael Apted.
- YEAR: 1996.
- ANALYSIS: Dr. Guy Luthan (Hugh Grant) is a resident collaborating with the prestigious neurologist Lawrence Myrick (Gene Hackman) in a research project. Dr. Luthan is surprised when he observes how a series of homeless patients arrive at the emergency room with extremely strange and severe neurological symptoms that end in death. Finally, he discovers there is a perfectly organised secret scheme behind these cases. Dr. Myrick is in charge of the plot and he and his accomplices intend to obtain hefty profits with the research. Dr. Luthan does not accept these unacceptable experiments.

Clinical case

In April 2020, Dr. Prieto was working in the emergency department of a hospital. At that time, due to the Covid-19 pandemic, she and other healthcare personnel were not provided with all the necessary protective material needed to care for patients, owing to the shortage of personal protective equipment (PPE) and masks. Dr. Prieto believes that the overwhelming number of Covid-19 patients in the emergency room and the lack of appropriate protective material puts not only her health and that of other medical personnel at risk, but also the health of their relatives and of other patients they treat, because if she gets infected with SARS-CoV2, she can in turn infect others both at work and at home. Dr. Prieto decided to consult this issue with the Ethics Committee for Healthcare at her center. She asked them if, given the situation she described, she is obliged to treat patients with Covid-19 (or those suspected of being infected) in the emergency room regardless of whether she has adequate protection.

Ethical Analysis

Throughout the pandemic, the information regarding COVID-19, the preventative measures and the available resources have varied. There have been shortages of PPE in hospitals, in home health care services, and in outpatient facilities, which have led to many professionals questioning how far their duty of care should go since, if it puts not only them but others at risk, it cannot be considered an absolute duty. Providing assistance in an emergency situation is an ethical and legal obligation, so every citizen must undertake it as long as there is no present risk to themselves or to any third party. However, for a healthcare professional, this duty is even more important. Thus, if a healthcare professional refuses to act in an emergency situation the penalties for not doing so would be much more severe.

In Spain, in addition to being an ethical and legal duty, the duty of care (and of non-abandonment) is also a deontological obligation. The Medical Code of Ethics states that “The primary duty of a doctor is to the health of their patient, so this duty must take precedence over any other interest. A doctor cannot refuse care

for fear that the illness or patient's circumstances pose a personal risk". It also establishes that "A doctor will not abandon any patient who requires their care, even in a catastrophe situation or epidemic, unless obliged to do so by a competent authority; or if there is an imminent and unavoidable risk to their life. A doctor shall voluntarily collaborate and give medical assistance".

Therefore, the matter would be to focus on putting all the means available and using the most up-to-date information regarding the disease at their service, in order to minimize the risk for health care professionals as much as possible while at the same time guaranteeing care to the patients.

Possible courses of action

- Prioritize patient care above all else, even if there is a lack of adequate personal protection equipment.
- Reuse and make the most out of whatever means are available. Even when they are used for longer than the recommended equipment life-span, according to normal protocols.
- Try to limit the number of medical personnel treating directly with Covid-19 patients (or those suspected of having Covid-19), so as to make the personal protective equipment available last as long as possible. In addition, treat the patient as effectively and quickly as possible (in order to reduce the risk of infection).
- Refer sick patients to other health centers.
- Use remote medical treatment systems (telemedicine), specifically the use of the phone, as this is the only available means to treat patients remotely in the emergency room.
- Not treat patients until you are provided with the proper personal protective equipment in order to guarantee your safety.

Recommended courses of action

- In the first place, call for the administrative authorities to increase professional protective resources as much as possible.
- Make the most out of available materials (without overusing them or using them beyond what the protocols indicate).

- Try to have as few health care professionals as possible come into contact with COVID-19 patients (or those suspected of having COVID-19) for as short of time as possible, in order to make the existing material last as long as possible and to reduce the risk of contagion.
- If and when possible, refer the sick to other health centers with more resources.
- When possible, use remote medical systems (telemedicine), specifically the telephone, to interact with patients, thus using less PPE, optimizing their use, and reducing risks.
- If, despite the aforementioned measures, health professionals still face specific situations of serious and imminent safety risk to the patient and probable but not imminent safety risk to the doctors, they should still provide care. Doctors should take all precautionary measures available while caring for the patient, in order to avoid patient abandonment. The assessment of these parameters (seriousness, risk to the patient, and risk to the professional) must be responded to with strictly clinical criteria.

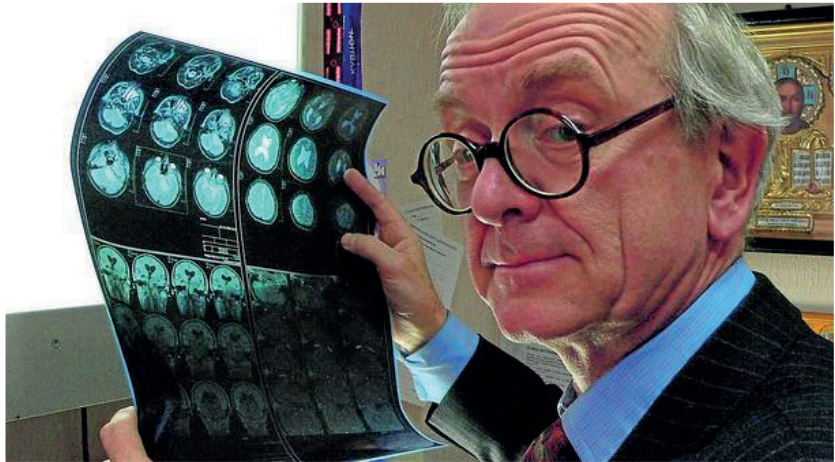
Discussion

Not abandoning a patient in an emergency situation, in this case due to a pandemic, is an ethical, deontological and legal duty in compliance with the legal terms of obligation to provide assistance. That being said, no duty is absolute. Rather, it is a question of analyzing the health risk to the doctor (and therefore, to their environment) and whether this risk is an exception to the duty of care or non-abandonment required from the health care provider. In this regard, the Spanish Medical Association (Organization of Medical Colleges, OMC) published a document on April 1st that included the obligatory mandate for health care professionals to provide care for patients despite the lack of adequate protective equipment, recalling the obligation by the doctor to the duty-of-care with their patients. Even so, 48 hours after this was published, the document prepared by the OMC was widely rejected by a large majority of the association and thus the OMC withdrew the document, arguing that the document had been perceived as questioning the commitment and professionalism of thousands of doctors and medical personnel. A second document insisted, logically, that it goes without saying that health authorities need to provide sufficient personal protective equipment (PPE) for all health professionals. This was also stated in the Health Ministry's report (April 2nd): "The availability of officially approved PPE for all health care professionals on the front line in the fight against the pandemic must be guaranteed."

Recognizing that the obligation by healthcare professionals regarding the duty of care and non-abandonment of a patient is not absolute (none is), as heroic attitudes cannot be demanded from our health professionals; the question is rather about seeing how Dr. Prieto should act in the emergency room. During the pandemic, healthcare professionals have faced situations implying a clear risk to their health for being in close contact with infected persons lacking the appropriate protection material. This risk should be studied and assessed for each specific situation to decide, depending on what the available resources are, which professionals should use the available PPE, the type of contact that should be had with the patient (the least amount possible), and if in addition to all that, the care for the patient may be provided by telemedicine.

This case has been studied in accordance with the Spanish current legislation, therefore its resolution can vary in other regulatory frameworks.

For reflection:



- FILM: *The English Surgeon*.
- DIRECTOR: Geoffrey Smith.
- YEAR: 2007.
- ANALYSIS: This is a documentary about neurosurgeon Henry Marsh. This doctor has travelled during many years to Ukraine trying to improve the neurosurgery service in that country. He is convinced that the priority is to train Ukrainian doctors in order to improve the healthcare system, instead of exporting medicine as if it were mere charity. He has had to face many dramatic cases in which the doctors' professionalism is put to test, raising the question of where the limits to the medical healing duties lie. Henry Marsh gives a very humane idea of the relationship doctors should have with their patients.

Clinical case

It is the first week of April 2020. Andrés, a 32-year-old internist who has only been practicing for a short time, works at a secondary-level hospital on guard shifts. But due to Covid-19, he joined an internal medical team working exclusively with Covid-19 patients at the end of March. The team meets every day for a clinical session where they discuss incidents that have happened and the progress of the disease. Of course, as in every hospital, this situation is new for everyone and they are learning as they go. In their centre, patients admitted for respiratory failure are administered hydroxychloroquine and lopinavir/ritonavir, and if they show no sign of response after 48 hours or if there is a worsening in their condition, they then consider using tocilizumab or interferon. In reality, they are treating patients without scientific proof, as there is no evidence to indicate whether any of the drugs used (hydroxychloroquine, lopinavir, ritonavir, interferon, tocilizumab) are effective for treating SARS CoV-2. Their use is based on the characteristics of the drugs, that is, on their theoretical, potential effect on the coronavirus. During one clinical session, the head of infectious diseases brings up the possibility of conducting clinical trials with patients to see if the empirical therapy they are using is actually useful for the patients. After discussing it, they decide to join an international clinical trial. The patients participating in the clinical trial will only receive one of the drugs that they have used until now. The following day, Andrés attends a new patient who has just been admitted. His name is Pedro, a 63-year-old patient who was admitted due to respiratory failure caused by Covid-19. Andrés has doubts about what he should do: should he start treatment with hydroxychloroquine and lopinavir/ritonavir and if the patient (Pedro) doesn't respond well, should he suggest interferon and/or tocilizumab? Or, does he suggest for Pedro to participate in the clinical trial? What if, when participating in the clinical trial he gets a drug that doesn't work, which in turn deprives him of another one that does? Andrés thinks, if he gives him all the drugs, maybe one of them could work.

Ethical analysis

In this case, the difficulty of the decision is due to the fact that the prescription of the drugs included in the protocols at that centre is done empirically and without scientific backing. Also, if Pedro is included in the trial he may be deprived of

receiving another type of beneficial treatment. The latter is what is causing the moral dilemma for Andrés because he feels that if he includes him in the trial he would not be doing everything in his power to help Pedro. However, administering drugs without scientific evidence does not help him medically either, while a well-designed clinical trial cannot only benefit Pedro but many other patients as well. Therefore, the best course of action would be to offer the patient the possibility of participating in the clinical trial and obtain their consent as, according the information provided, Pedro appears to be capacitated and competent to make this decision.

Possible courses of action

- Start the treatment they are using with all patients now, without any scientific proof: hydroxychloroquine, and lopinavir/ritonavir (+/- interferon and/or tocilizumab).
- Inform Pedro about the clinical trial and include him only if he consents after clarifying any doubts he may have.
- Include Pedro in the clinical trial without informing him, since this is an urgent situation and the good of the public justifies including Covid-19 patients in clinical trials.
- Include Pedro in the clinical trial after getting consent from his family/relatives (consent by proxy).
- Include Pedro in the clinical trial and obtain consent at a later stage (if/when Pedro improves).
- Do not give Pedro any treatment as there is no scientific evidence proving any of the drugs are beneficial, and instead wait for the results of the clinical trials.

Recommended courses of action

- Inform Pedro about the clinical trial and only include him if after clarifying any doubts, he gives his consent. Pedro's informed consent would then need to be, if the circumstances permit it, both verbal and written. This recommendation is justified since there is no proven effective treatment, making it important to conduct clinical trials so that an effective treatment can be found. It would be crucial that the clinical trial offered to Pedro have the necessary scientific and methodological guarantees.

- If Pedro declines to participate in the clinical trial, he should then be offered to start treatment with hydroxychloroquine and lopinavir/ritonavir (+/- interferon and/or tocilizumab). However, before starting the treatment, he must be informed that these treatments have not been scientifically proven to be effective and that they have side effects. Thus, he must consent to the start of such treatments. If the circumstances allow it, this informed consent should also be both verbal and written.
- All of this must be registered in his medical history record.

Discussion

When considering whether to include a patient in a clinical trial, it must be borne in mind that the objective of the research is the advancement of science and that, furthermore, a potential benefit to the subject should be sought. Therefore, research on human beings cannot be done without respecting some minimal ethical boundaries, some of which are listed here: 1) obtaining the informed consent of the participant for the inclusion in a clinical trial; 2) the design of the study must have social value and serve to broaden scientific knowledge; 3) the design of the study must be scientifically valid so as not to subject the patients to useless research; 4) the selection of patients must be fair and subjects cannot just be selected due to their vulnerable condition; 5) the risks and benefits should be assessed for each candidate and if the risks outweigh the benefits, the patient should not be included in the trial (the research should not be maleficent). What's more, all clinical trials must be independently evaluated and approved by external committees. In Spain, the trials need to be approved by both the Spanish Agency for Medicine and Health Products (AGEMED) and the corresponding Ethics Committee for Drug Research (CEIm).

The emergence of the SARS-CoV-2 pandemic has caused us to face an unknown disease for which there is no effective treatment. This, together with the large number of people affected and the high mortality rate, has led to treatments being prescribed without scientific evidence (in fact, they are highly likely to cause more harm than good) and the urgent consideration for clinical trials. A public health emergency like this can lead to relax certain ethical principles; for example, in certain cases, the written informed consent for clinical trials could be dispensed with, or certain administrative procedures could be expedited seeking to favor progress in the research. However, this should not be the case. The urgency of the pandemic should not justify overlooking basic ethics, both in healthcare and with respect to research that involves human beings. The flexibility required by the pandemic should not break our basic ethical standards, without which, the health-

care and research involving human beings would cease to make sense. Informed consent (with or without a written form) when doing research involving humans, the individualized assessment of the risks and benefits for the patient are among the essential ethical basics.

This case has been studied in accordance with the Spanish current legislation, therefore its resolution may vary in different regulatory frameworks.

For reflection:



- FILM: Contagion.
- DIRECTOR: Steven Soderbergh.
- YEAR: 2011.
- ANALYSIS: This is a film about the fast spreading of a virus that can be lethal, a situation which causes a global crisis. 48 hours after returning from Hong Kong, Beth Emhoff (Gwyneth Paltrow) dies from a series of symptoms and a high fever of unknown origin. Similar cases multiply in different countries without a clear cause and lacking an effective treatment. This situation unleashes widespread alarm. It is a case of an enormously aggressive virus which will take the lives of 26 million people. Contagion gives us an idea of the various interests that are at stake when facing a public health problem: not only healthcare issues but also political, economic and social ones. The medical community tries to solve the scientific questions, find the way to research the case and at the same time give the best treatment possible to the sick. Meanwhile, the public authorities try to appease the population.

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